

Lupus News

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Don't Forget
Your
Sunscreen!

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UNDERSTANDING FATIGUE IN LUPUS— AND WHAT CAN BE DONE



If you have lupus, you probably know how bad fatigue can be. It's one of the most common symptoms reported by people with lupus. Most lupus patients suffer with it. But exactly **what causes this fatigue that goes far beyond just being tired?**

A study done at Hospital for Special Surgery some years ago suggested that depression and sleep problems might contribute to fatigue in people with

Lupus.^[1] But in the women studied, those who had lupus did not have more depression than those who did not have lupus. However, those who had lupus took longer to fall asleep—and slept for longer periods of time.

Over the years, other researchers have also tried to figure out how sleep and depression might play a role. Others have suggested that lack of exercise might be involved—because exercise can actually give you energy when your muscles get fit.

New Research

A Canadian group of researchers explored the question of fatigue and reported at a meeting of the American College of Rheumatology [2] They studied 100 women with lupus who were given a series of different tests to look at the type of their fatigue; how bad their fatigue was; how bad their pain was; whether they were de-

pressed—and if so how badly; how well—or poorly—they slept; how much physical activity they did in their leisure time; whether they were satisfied with the support they received from family and friends.

Finally, the women were examined by a doctor to check the level of their lupus disease activity and the impact lupus already had on their bodies.

What They Learned

As in other studies, they found that people with lupus have much more fatigue than others.

Fatigue can be influenced by everything they explored and more including depression, pain, quality of sleep, quantity of sleep, exercise, severity of illness, and satisfaction with your social support network—as well as flares, medications, and stress. And it varies from one

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Patty Powell Event Coordinator

Our annual "Walk the Loop for Lupus" Walk-a-thon was held at Reid Park on March 17, 2012 and it was our biggest and best event ever! We had nearly 800 walkers and I believe because it was on St. Patrick's Day it had such a festive atmosphere from the very start.

So many people came dressed in costumes and were definitely ready to have some fun! It was a real family event.

We had a beautiful day complete with great food, music, things to buy, prizes to win, and balloons to launch in honor of loved ones with Lupus.

It was an awesome time! Thank you Tucson for our best event ever!!

Patty

From the President....

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.

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Can you believe we are starting the fifth month of 2012 already? What an eventful Spring we have had!

We began the year with a new website. We'd like to give special thanks to Pederson Design Group for all of their hard work on the first phase of our new website. It is very functional and user friendly and made the Walk registrations go very smoothly. Thank you Arlene and Christo! Our Walk the Loop for Lupus was delightful and we had our largest turnout yet. With beautiful weather, we enjoyed the luck of the Irish. Also this spring we had an event at Sir Veza's at Tucson Mall, where we sold raffle tickets for the 100% Electric Nissan Leaf. The drawing for the car was at the end of April. Though we did not sell the winning ticket, we did make about \$2500 with that fundraiser. Thank you Jim Click! Thank you faithful supporters!

If you are interested in making a gift of appreciated stock or naming the foundation in your will or trust, please call the office and leave me a message. I will contact you directly to answer any questions or give you more details.

We have been invited by El Tour de Tucson to be one of their charities for this year's November 17th event. We are looking for riders to join our team. Please let us know if you are interested in riding for us this year, or know of someone who would be. We are just starting to formulate our plans on the El Tour but we already know we need **you** to make it **work!** Please contact the office if you are interested in joining us this year.

Have a wonderful Summer. It has been a busy Spring, and I am looking forward to the long, slow days ahead.

Joni



November 17, 2012

UNDERSTANDING FATIGUE... CONT'D FROM PG 1

patient to the next. Because fatigue arises from so many different factors, they said it is important to find out what factors were involved in the patient being treated—and treat all of them to get at the fatigue. These factors can be treated –modified-changed.

Two Types of Fatigue

One thing that was different about their study was that **they separated physical fatigue from mental fatigue**. Many other studies have just looked at “fatigue” as one thing.

Think of physical fatigue as “I’m too tired to stand up,” or “I just can’t walk another block.” That’s easy to recognize—and you should listen to it. Rest. Sit down or just collapse in bed for awhile.

Mental fatigue can be more difficult to get a grasp on sometimes. “I can’t think straight” or “I can’t concentrate” or “I keep rereading this paragraph again and again” may be mental fatigue. Or it may be a sign of the cognitive (thinking) difficulties that are part of neuropsychiatric lupus. So any changes in your thinking or concentration should be reported to your doctor—because a change in medication may help. In the meantime, again, rest. Put the book down. Veg out in front of the TV. Cuddle up with your pet. (Studies have proven that stroking a pet can be very relaxing.) Or take a nap.

Physical Fatigue

It was not a surprise that people with more pain and proper sleep were more likely to have physical fatigue.

Much research in people **without** lupus has shown exercise helps reduce depression. But this study had an interesting surprise. Only the lupus-fatigued women who did not score high on depression tests seemed to be helped by exercise. Lupus-fatigued women who were depressed did not get an improvement in physical fatigue from exercise. Does this mean you shouldn’t exercise? No! You

need exercise for heart fitness, muscle strength and to keep up your energy. It may even help your physical fatigue—because a finding from one research study doesn’t apply to everyone.

But look to other means as well. Talk with your doctor about ways to improve your sleep and lower your pain level, especially by reducing your disease activity.

Mental Fatigue

The factors most related to mental fatigue were slightly different. They were clearly:

Greater pain severity—again, talk with your doctor about how to reduce your pain level.

Higher levels of depression—ask your doctor about referral to a licensed psychotherapist such as a social worker or psychologist. In some cases, antidepressant medication may also be useful.

Lower satisfaction with social support networks—talk with family and friends about what you need from them. Often they may not be aware of how you are feeling inside. Let them know what can help. Establishing an understanding together of the impact of fatigue and how to problem-solve around this is important..

How Do You Cope

Fatigue is profound. It touches you to the core. It can totally disrupt your life. Fatigue itself can be stressful. Because you cannot “see” fatigue, and it can change so much from hour-to-hour and day-to-day, your fatigue can also be confusing to those with whom you live and work. But it’s not something you can point to like a swollen joint or a rash. You can be exhausted with fatigue and your friend or family member says, “You look great.”

This can be very frustrating. You feel that others just don’t get it. Over time, see if you



can learn to respond comfortably and assertively to such comments. “I wish I felt as great as I look—but I’m really fatigued right now, and it’s important that I rest and take care of myself.”

Those words may not be right for you—but you need to find the words that are. Because when fatigue hits, you need to let go and rest. Give in to fatigue when necessary—so you can spring back. Take that temporary break—so you can stand up and think clearly later. Whether it’s an hour later or a day later doesn’t matter. You will find the right moment. And only you can. Because lupus fatigue is different for everyone—what causes it, when it hits, what helps, when it goes.

Be kind to yourself, work with your doctor, and you will find the path that’s best for you. Just don’t give up.

[1] McKinley P’S, Ouellette SC, Winkel GH. The contributions of disease activity, sleep patterns, and depression to fatigue in systemic lupus erythematosus. A proposed model. *Arthritis Rheum.* 1995 Jun;38(6):826-34.

[2] Da Costa D, Bernatsky S, Pineau C, Lowenstyn I, Menard H, Dritsa M, Dobkin PL, Clarke AE. Dimensions of Fatigue in SLE: Relationship to Disease Activity, Behavioural and Psychosocial Factors. *Arthritis Rheum.* 2003 Sep;48(9):S185. Abstract #387.

Our Thanks to Hospital for Special Surgery
hss.edu



Walkathon 2012



November 17, 2012



Walkathon 2012



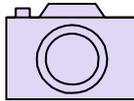
Thank You !!

To the official Walk Photographers :

John Poole of
John Poole Graphic Design

And

Lee Van Winkle of
Rembrandt Photography



November 17, 2012



Benlysta[®]
(belimumab)
For Injection 120 mg/vial

ARE YOU OR SOMEONE YOU KNOW LIVING WITH LUPUS?

YOU'RE INVITED to take part in the first event of its kind!

Please Register for this Event. A Representative from GlaxoSmithKline will be flying in to present an Educational Presentation on the new drug BENLYSTA.

When: Wednesday July 18, 2012

Time: Speaking promptly at 11AM

Where: Lupus Office
4602 E. Grant Road
(Grant & Swan, directly across street from Applebee's)

Please call our office at: **520-622-9006** to register.

BENLYSTA is a prescription medication used to treat adults with active systemic lupus erythematosus (SLE or lupus) who are receiving other lupus medicines.

It is not known if BENLYSTA is safe and effective in people with severe active lupus nephritis or severe active central nervous system lupus, and it has not been studied in combination with other biologics or intravenous cyclophosphamide. Use of BENLYSTA is not recommended in these situations.

Important Safety Information

BENLYSTA can cause serious side effects. Some of these side effects may cause death. It is not known if BENLYSTA causes these serious side effects. Tell your healthcare professional right away if you have any symptoms of infections (such as fever, coughing up mucus, and/or burning on urination), heart problems (such as chest pain or shortness of breath), or mental health problems (such as thoughts of suicide, trouble sleeping, anxiety, or depression) while receiving BENLYSTA.

Do not receive BENLYSTA if you are allergic to belimumab or to any of the ingredients in BENLYSTA.

November 17, 2012



Lupus Support Group Schedule

February	Diagnosis & It's Impact on You
March	Understanding Lab Tests
April	Red Flags!
May	Helpful Hints
June	Stress & Lupus
July	** Benlysta Guest Speaker
August	Exercise
September	Diet & Nutrition
October	Stress
November	Holiday Helpful Hints

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

Weds May 16th	Weds Aug 15th
Weds June 20th	Weds Sep 19th
Weds July 18th	Weds Oct 17th

For additional details call the office at 622-9006 or email us at lupus12@juno.com

November 17, 2012



** See Page 6 Benlysta
event

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

MEDICAL ARTICLES LIBRARY

QUARTERLY NEWSLETTER

TUCSON SUPPORT GROUPS

Held 3rd Wednesday

DOUGLAS AREA SUPPORT GROUP

Held Monthly - 520-364-5028

YOUTH SUPPORT

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

*Become a Tour de Tucson Rider for Lupus!
Call Us Today!!*

11-17-12



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