



Lupus News

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ENGLISH TRANSLATION OF...

Gloria Rosso White's
"Coping with Lupus..."

"El hacer frente al lupus es un desafío que tengo a diario;

algunos días son buenos y otros son muy difíciles."

By Gloria Rosso White

Mi nombre es Gloria y se me ha pedido compartir la historia de mi vida con Lupus. En la primavera del año 2002, me entere de que tenía una enfermedad crónica que los doctores llamaron Lupus Sistémico Eritematoso. En ese momento, trabajaba en el programa bilingüe de un jardín de infantes como profesora de tiempo completo. También trabajaba los fines de semana en una librería. Era una persona muy sana; comía saludablemente y además hacía ejercicio regularmente. Era joven y llena de energía y nunca pensé que podría enfermarme de la manera en que lo hice.

Quisiera compartir que nací y me crié en Argentina, y en 1992 vine a este país como profesora de intercambio. Después de terminar mi licenciatura en enseñanza, me casé y comencé una nueva vida aquí. Tenía los problemas diarios que cualquier persona tiene: horario, dinero, tráfico, días con cabello rebelde. Estoy segura que los que sufren de enfermedades crónicas saben lo que significa cuando menciono esto. Ahora, miro atrás y esos problemas triviales me causan risa.

*Y siento un día más cercano el milagro
que mucha gente como yo, desea - una cura para el lupus.
¡Esa esperanza me sostiene! — Gloria Rosso White*

Los doctores dicen que todo comenzó con un virus – un virus común. En el plazo de dos semanas, mis riñones comenzaron a funcionar incorrectamente. Los síntomas que más recuerdo son la fatiga que no se iba sin importar cuanto intentara descansar, la inflamación en mi cara, dolor en mis coyunturas y náusea constante. Me deshidraté y fui hospitalizada. Durante esa semana, una biopsia de mis riñones determinó que tenía nefritis del lupus (riñones afectados debido al lupus). Cuando recibí la noticia, no sabía mucho sobre lupus pero pensé, "Soy joven y soy fuerte, yo puedo superar esta enfermedad".

Mis doctores me medicaron con esteroides y una droga de quimioterapia, y volví a mi casa a recuperarme. Los efectos secundarios de la medicina fueron muy fuertes. Aumenté treinta libras de peso en cuatro días debido a la hinchazón, no podía dormir en la noche y tenía oscilaciones incontrolables de humor. *Continued on page 2...*

Lupus News

LUPUS FOUNDATION OF MINNESOTA
2626 East 82nd Street, Suite 135
Bloomington, MN 55425

MISSION STATEMENT: The Lupus Foundation of Minnesota is a 501(c)(3) nonprofit charitable organization that provides education, support and service to those affected by lupus, promotes awareness and understanding of lupus to others and supports research that seeks to improve the diagnosis and treatment of lupus as well as to discover its cause and cure.

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“Coping with lupus...” By Gloria Rosso White

Me hinché tanto que mi anillo de bodas tuvo que ser cortado de mi dedo para liberar la presión. Sin embargo poco a poco, la enfermedad respondió al tratamiento y comencé a sentirme mejor. Continuaba diciéndome a mí misma, “Prometí a mis estudiantes que iba a estar con ellos pronto - necesito guardar mi promesa y acabar el año escolar”. Un mes después, pude ir a trabajar nuevamente por algunas horas y estar con mis pequeños del kinder durante el último mes de escuela. Excepto por la inflamación en mi cara y pies, y mi pérdida de cabello, no parecía muy enferma. El haber regresado a la escuela y recuperar algo de normalidad en mi vida, hizo una enorme diferencia – y con el cuidado y el estímulo de mi familia y amigos, me recuperé bastante rápido. Para el otoño, el lupus había entrado en remisión; y a pesar de haber perdido mi cabello y tener menos energía, me sentía bastante bien. En los tres años después de mi diagnóstico mi condición fue, de modo general, buena. Tenía análisis de sangre rutinarios y veía al especialista del riñón regularmente. Comencé a hacer ejercicio otra vez y me uní a una clase de levantamiento de pesas. Después de dos años y medio, dejé de tomar la medicina con esteroides y todas las pruebas demostraron que la enfermedad estaba bajo control. Sentía que el lupus había sido solamente una mala pesadilla en mi vida.

En septiembre de 2004, mi marido y yo fuimos a la caminata de Lupus. Después de escuchar las experiencias de otros pacientes con lupus, noté que no me había ido tan mal como a la mayor parte de la gente allí. Poco sabía de las malas cosas que vendrían para mí en el año siguiente.

Varios factores condujeron al segundo brote. Me recuperaba de una infección, trabajaba largas horas debido al fin de año escolar, y estaba lidiando con algunas noticias con respecto a otro aspecto de mi salud que me apenaban. Siempre pensé que sería fácil reconocer el lupus si volvía y no esperaba que se reactivara porque había seguido mi régimen de tratamiento fielmente. Pero regresó, y los síntomas eran lo suficientemente diferentes como para que los doctores pensarán que era algo más. Pasé un mes postrada en cama en casa mientras los doctores intentaban una cosa tras otra. Finalmente me deshidraté a tal punto que tuve que ser hospitalizada y fue entonces que diagnosticaron un brote (o rebrote) de lupus. Desafortunadamente, mi segundo episodio fue mucho más severo que el primero. Pasé un mes en el hospital, mi función del riñón cayó hasta apenas un 10% y me pusieron en diálisis. Fue determinado que mi lupus ahora era clase IV, y mis doctores sospechaban que otros órganos además de mis riñones habían llegado a estar implicados. Me dieron el mismo tratamiento que antes, aunque esta vez no respondió enseguida. Sentía que estaba en un laberinto sin salida.

Eventualmente la medicina comenzó a mostrar progresos; no necesité más el tubo de alimentación y me dieron de alta del hospital, continuando diálisis como paciente externo. Los dos meses que siguieron fueron muy difíciles y estoy segura que no habría conseguido superarlos si no hubiera sido por el asombroso apoyo y ayuda que recibí de mi familia, mis amigos, mis colegas, y mis estudiantes. Un mes después de que me dejaron de hacer diálisis, estaba lo suficientemente fuerte como para regresar a trabajar y en el plazo de seis meses el lupus entró en remisión de nuevo.

Después de este segundo brote, quedé con muchas condiciones residuales que no tuve después de mi primera vez (dolor en las articulaciones, fatiga crónica, insomnio, colesterol alto, etc.).

El hacer frente al lupus es un desafío que tengo a diario; algunos días son buenos y otros son muy difíciles. No es una batalla que alguna vez deseé luchar y aun sigue siendo duro para mí aceptar que tengo lupus. Diariamente cuando consigo hacer la mayor parte de las cosas que una persona regular hace, siento que he logrado algo muy importante. Y siento un día más cercano el milagro que mucha gente como yo, desea – una cura para el lupus. ¡Esa esperanza me sostiene!

English Translation:

“Coping with lupus is a challenge that I face every day; some days are good and some are not.”

My name is Gloria and I've been asked to share the story of my life with Lupus. In the spring of 2002, I learned I had a chronic disease that the doctors called Systemic Lupus Erythmatosus. At the time, I was working in a bilingual

Kindergarten program as a full time teacher. I also worked over weekends at a bookstore. I was a very healthy person; I watched what I ate and I also exercised regularly. I was young and full of energy, and I never thought that I could get as sick as I did.

I was born and raised in Argentina, and in 1992 I came to this country as an exchange teacher. After finishing my teaching licensure, I got married and started a new life here.

I had the everyday problems that any person has: schedules, money, traffic, bad hair days. I'm sure that those of you who suffer from chronic disease know what I mean when I say that, now, I look back on those trivial problems and I laugh.

The doctors say it all started with a virus, a common virus. Within two weeks, my kidneys had begun to malfunction. The symptoms that I remember most were fatigue that would not go away no matter how much I tried to rest, puffiness in my face, pain in my joints, and constant nausea. I became dehydrated and was hospitalized. Within a week, a biopsy of my kidneys determined that I had Lupus Nephritis. When I got the news, I did not know much about lupus but I thought to myself, “I am young and I am strong, I can overcome this illness.”

My doctors put me on steroids and on a chemo drug, and I came back home to recover. The side effects of the medicine were very tough: I gained thirty pounds from the swelling in four days, I could not sleep at night and I had uncontrollable mood swings. I was so swollen that my wedding band had to be cut off my finger to release the pressure. Little by little, however, the disease responded to treatment and I began feeling better. I kept telling myself, “I promised my students that I was going to be back soon, I need to keep my promise and finish the school year.” A month later, I was able to go back to work part-time and be with my kindergartners for the last month of school. Besides my swollen face and feet and my hair falling out, I did not look very sick. Being back at school and regaining some normality in my life made a tremendous difference and with my family and friends' care and encouragement I recovered fairly quickly. By fall the lupus had gone into remission and except for having lost my hair and having less energy, I felt quite well. The three years after my diagnosis were, in general terms, good. I had routine blood checkups and saw a kidney specialist regularly. I started exercising again and joined a weightlifting class. After two and a half years, I went off the steroid medicine and all the tests showed the disease was under control. I felt lupus had been just a bad nightmare in my life.

In September of 2004, my husband and I went to the Lupus Walk. After listening to the experiences of some other lupus patients, I realized that I had not fared nearly as badly as most of the people there. Little did I know how bad things would get for me in the coming year.

Several factors led to the second flare; I was recovering from an infection, working long hours to finish the school year, and dealing with some distressing news regarding other aspects of my health. I always thought that it would be easy to recognize Lupus if it came back; I didn't expect it to recur because I had followed the treatment regimen faithfully. But it did, and the symptoms were different enough that the doctors thought it was something else. I spent a month bedridden at home while my doctors tried one thing after another. I finally became so dehydrated that I had to be hospitalized and that's when they diagnosed a flare. My second bout was much more severe than my first. I spent a month in the hospital, my kidney function dropped to just 10% and I was put on dialysis. It was determined that my lupus was now Class IV, and my doctors suspected that other organs besides my kidneys had become involved. I was given the same treatment as before, though this time it did not respond right away. I felt like I was in a maze with no way out.

Eventually the medicine started making progress, I did not need a feeding tube anymore and I was discharged from the hospital, continuing dialysis as an outpatient. The two months that followed were very difficult and I am certain that I would not have gotten through them if it had not been for the amazing support and help I received from my family, my friends, my colleagues, and my students. A month after I went off dialysis, I was strong enough to go back to work and within six months the lupus went into remission once again. *Continued on page 3...*

Funding for Marette's Angels Fund Complete



Bill and Linda Flies
FOUNDERS OF MARETTE'S ANGELS FUND

Marette Flies cared deeply about people with lupus. With insight and maturity beyond her years, she often wrote about the challenges she was overcoming with her own lupus. Much of this was published so that she could share her experiences with those traveling a similar course. Marette's empathy and encouragement meant much to the many members of the Lupus Foundation who were privileged to know her, especially young people like herself whose lupus rudely encroached on their active lives. Sadly, Marette had too few years in which to practice her compassion and understanding for others. But her inspiration lives on thanks to the thoughtfulness and generosity of Marette's family.

In April of 2002, Marette's parents, Bill and Linda Flies, made the first of five annual major contributions to form Marette's Angels Fund. The purpose of this fund is to support having a licensed social worker as part of the Foundation's staff.

In their own words, Bill and Linda expressed this tribute to Marette, "We feel blessed to have this opportunity to establish Marette's Angels Fund and help advance the important services that the Lupus Foundation extends to those with lupus. We are simply continuing the sincere concern and assistance that Marette extended to others with lupus. Her efforts to increase the public's awareness of lupus and to solicit the public's acceptance and assistance are well documented. The Foundation's use of our previous gift to publish the lupus newsletter was well placed and would please Marette immensely. We believe that this fund will have similar far reaching benefits."

In 2006, Bill and Linda made the fifth and final contribution, in total providing an amount that has already supported LFM's social worker position for the past four years, and in all likelihood will last another six years or more. It is humbling for the Foundation to receive and be the caretaker of such an important gift. All of us here feel Marette's spirit and her clarity of purpose at work guiding the stewardship of Marette's Angels Fund. We are indeed grateful for the kindness of Bill and Linda Flies and the inspiration of Marette's memory.

Attitude Is Everything

By Lina Wade, LFM OFFICE SERVICES COORDINATOR/EDUCATION SPECIALIST

There once was a beautiful woman who woke up one morning, looked into the mirror, and noticed that she had only three hairs remaining on her head. "Well," she said, "I think I'll braid my hair today." So she braided her hair and had a marvelous day.

The next morning, she got up, went to the mirror and there were only two hairs left on her head. "Hmm," she said, "today I think I'll part it down the middle." So she did and she had a great day.

On the third day, she got out of bed, looked in the mirror and realized that she had only one hair left to speak of. "Okay," she said, "I'm going to wear my hair in a pony tail today." She did and she had a fun, fun day.

The next day she woke up, took a glimpse and noticed that there wasn't a single hair remaining. "COOL!" she exclaimed, "I don't have to fix my hair today!"

Attitude is everything.

It's difficult for many of us to accept the fact that we have a chronic illness. When the reality sets in, we become consumed with the idea that we're no longer like others. We tend to focus on the illness, which is just a *component* of who we are. Our lives are being stolen by this negative outlook.

Adopting a positive attitude, on the other hand, can change things. It's important to do what you love – enrich life through means such as hobbies, good deeds or a fulfilling job. Use your valuable time for constructive activities and thoughts instead of for destructive behaviors and ideas. Rise each morning prepared to accomplish goals and feel happy.

A positive attitude works wonders for the mood, and you can have one! If you decide to go on a trip, play with your pet or take up a hobby, you may be surprised at the rewards. Pets love us and don't care that we're chronically ill. Being needed makes us feel better about ourselves. On a vacation, we can delight in different atmospheres, meet new people and see new things. There's always something new to learn! We don't have to be so preoccupied with illness.

We can live long, happy and productive lives – and it begins with the right attitude.

So...Be kinder than necessary – everyone you meet is fighting their own battle.

Live simply. Love generously. Care deeply. Speak kindly.

And have a good day!

"Coping with lupus..." By Gloria Rosso White

Continued... After this second bout, I've been left with a lot of residual conditions that I didn't have after the first time (joint pain, chronic fatigue, insomnia, high cholesterol, etc.).

So coping with lupus is a challenge that I face every day; some days are good and some are not. It is not a battle that I ever wanted to fight and it is still hard for me to accept that I have lupus. Every day that I get through doing most of the things a regular person does I feel like I've achieved something. And I feel like we're a day closer to the miracle that a lot of people like me wish for: a cure for Lupus. That hope keeps me going.

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Questions and Answers about Raynaud's Phenomenon

Following is an excerpt from NIH Publication No. 06-4911

What Is Raynaud's Phenomenon?

Raynaud's phenomenon is a condition that affects the blood vessels in the extremities – generally, the fingers and toes. It is characterized by episodic attacks, called vasospastic attacks, in which the blood vessels in the digits (fingers and toes) constrict (narrow), usually in response to cold temperatures and/or emotional stress. When this condition occurs on its own, it is called primary Raynaud's phenomenon. When it occurs with another condition such as scleroderma or lupus, it is called secondary Raynaud's phenomenon.

Who Gets Raynaud's Phenomenon?

Although people of any age can have Raynaud's phenomenon, the primary form typically begins between the ages of 15 and 25. Women are more likely than men to have Raynaud's phenomenon. It appears to be more common in people who live in colder climates. This is likely true because people with the disorder have more Raynaud's attacks during periods of colder weather.

Although estimates vary, most studies show that Raynaud's phenomenon affects about 3 percent of the general population. For most, the symptoms are mild and not associated with any blood vessel or tissue damage.

Most people with Raynaud's phenomenon have the primary form, which is not associated with any underlying disease. In fact, in these individuals it is thought to be an exaggeration of normal responses to cold temperature and/or stress.

When Raynaud's phenomenon is caused by or associated with an underlying disease, it is referred to as secondary Raynaud's phenomenon. Secondary Raynaud's phenomenon tends to begin later in life than the primary form, typically after 35 to 40 years of age.

It is common for patients with a connective tissue disease to have Raynaud's phenomenon. It occurs in more than 90 percent of patients with scleroderma, and in about 30 percent of patients with systemic lupus erythematosus and with Sjögren's syndrome. Secondary Raynaud's phenomenon may also be associated with exposure to vibrating tools such as jackhammers, which cause trauma to the hands and wrists. And it may be linked to certain drugs, such as chemotherapy agents, or to chemicals such as vinyl chloride.

What Happens During an Attack?

Attacks of Raynaud's phenomenon are caused by an intensification of the body's natural response to cold. When a person is exposed to cold, the body's normal response is to slow the loss of heat and preserve its core temperature. Blood vessels in the surface of the skin are called thermoregulatory vessels because they react to changes in the ambient temperature. To maintain normal core temperature, these specialized blood vessels in the skin surface constrict and move blood from arteries near the surface to veins deeper in the body. But for people who have Raynaud's phenomenon, the thermoregulatory vessels overreact to cold exposure with sudden and intense spasmodic contractions of these small blood vessels that supply blood to the skin of the fingers, toes, ears, face, and other body areas.

Once an attack begins, a person may experience three phases (though not all people have all three) of skin color changes – typically from white to blue to red – in the fingers or toes. Whiteness (called pallor) may occur in response to spasms of the arterioles (small branches of an artery) and the resulting collapse of the arteries supplying the fingers and toes. Blueness (cyanosis) may appear because the fingers or toes are not getting enough oxygen-rich blood. Finally, as the arterioles dilate (relax) and blood returns to the digits, redness (rubor) may occur.

During the attack, the fingers or toes may feel cold and numb as blood flow to them is interrupted. As the attack ends and blood flow returns, fingers or toes may throb and tingle. Typically, the blood flow to the skin will remain low until the skin is rewarmed. After warming, it usually takes 15 minutes to recover normal blood flow to the skin.

The most common treatments and self-help measures are described below.

Non-drug Treatments and Self-Help Measures:

The following non-drug treatments and self-help measures can decrease the severity of Raynaud's attacks and promote overall well-being.

- **Take action during an attack.** You can decrease both its length and severity by a few simple actions. The first and most important one is avoid the cold. Warming the body and the hands or feet is also helpful. If you're outside and the weather is cold, go indoors. Run warm water over your fingers or toes or soak them in a bowl of warm water to warm them. If a stressful situation triggers the attack, get out of the stressful situation, if possible, and relax. While biofeedback and similar nondrug methods are used, formal studies have suggested they are not helpful.
- **Keep warm.** It is important not only to keep the extremities warm but also to avoid chilling any part of the body. Remember, a drop in the body's core temperature triggers the attack. Shifting temperature (for example, rapidly moving from 90 degrees outside to a 70 degree air-conditioned room) and damp rainy weather are to be avoided. In cold weather, pay particular attention to dressing. Several layers of loose clothing, socks, hats, and gloves or mittens are recommended. A hat is important because a great deal of body heat is lost through the scalp. Keep feet warm and dry. Some people find it helpful to wear mittens and socks to bed during the winter. Chemical warmers, such as small heating pouches that can be placed in pockets, mittens, boots, or shoes, can give added protection during long periods outdoors.

People who have secondary Raynaud's phenomenon should talk to their doctors before exercising outdoors in cold weather. In warm weather, be aware that air conditioning also can trigger attacks. Setting the thermostat for a higher temperature or wearing a sweater indoors can help prevent an attack. Some people find it helpful to use insulated drinking glasses and to put on gloves before handling frozen or refrigerated foods.
- **Do not smoke.** The nicotine in cigarettes causes the skin temperature to drop, which may lead to an attack.
- **Avoid aggravating medications** such as vasoconstrictors, which cause the blood vessels to narrow. Vasoconstrictors include beta-blockers, many cold preparations, caffeine, narcotics, some migraine headache medications, some chemotherapeutic drugs, and clonidine, a blood pressure medication. Some studies also associate the use of estrogen with Raynaud's phenomenon.
- **Control stress.** Because stress and emotional upsets may trigger an attack, particularly for people who have primary Raynaud's phenomenon, learning to recognize and avoid stressful situations may help control the number of attacks. Many people have found that relaxation can help decrease the number and severity of attacks. Local hospitals and other community organizations, such as schools, often offer programs in stress management.
- **Exercise regularly.** Many doctors encourage patients who have Raynaud's phenomenon – particularly the primary form – to exercise regularly. Most people find that exercise promotes overall well-being, increases energy level, helps control weight, and promotes cardiovascular fitness and restful sleep. Patients with Raynaud's phenomenon should talk to their doctors before starting an exercise program.
- **See a doctor.** People with Raynaud's phenomenon should see their doctors if they are worried or frightened about attacks or if they have questions about caring for themselves. They should always see their doctors if episodes occur only on one side of the body (one hand or one foot) and any time one results in sores or ulcers on the fingers or toes.

What Research Is Being Conducted to Help People Who Have Raynaud's Phenomenon?

Researchers are studying techniques such as laser Doppler imaging to better diagnose Raynaud's phenomenon and to predict and monitor its course and responsiveness to treatment.

They are also evaluating the use of new treatments to improve blood flow for those who have Raynaud's phenomenon. These include the high blood pressure drug losartan (Cozaar); prostaglandins such as iloprost and alprostadil (Caverject, Edex); the male erectile dysfunction drug sildenafil (Viagra); the blood-clot-preventing drug ticlopidine (Ticlid); and the herbal remedy ginkgo biloba.

Treatments such as L-arginine, taken orally, have been studied as a way to reverse Raynaud's-related damage to tissue in the toes and fingers, but they have been found ineffective in most studies.

Basic investigators are studying the molecular mechanisms behind Raynaud's phenomenon, the anatomy of blood vessels, and possible genetic associations. Researchers in scleroderma and other connective tissue diseases are also investigating Raynaud's phenomenon in relation to these diseases.

Where Can People Find More Information About Raynaud's Phenomenon?

- *National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse National Institutes of Health:*

1 AMS Circle

Bethesda, MD 20892-3675

Phone: 301-495-4484 or

Toll Free: 877-22-NIAMS (877-226-4267)

TTY: 301-565-2966

Fax: 301-718-6366

www.niams.nih.gov

The clearinghouse provides information about various forms of arthritis and rheumatic diseases and bone, muscle, and skin diseases. It distributes patient and professional education materials and refers people to other sources of information. Additional information and updates can also be found on the NIAMS Web site.

- *American College of Rheumatology:*

1800 Century Place, Suite 250

Atlanta, GA 30345

Phone: 404-633-3777

E-mail: acr@rheumatology.org

www.rheumatology.org

This professional organization of rheumatologists (doctors specializing in arthritis and related conditions such as Raynaud's phenomenon) and associated health professionals is involved in research, education, and patient care. It provides referrals to rheumatologists and other health professionals.

For Your Information

For updates and for any questions about any medications you are taking, please contact the U.S. Food and Drug Administration at 1-888-INFO-FDA (1-888-463-6332, a toll-free call) or visit their website at **www.fda.gov**.

NIH Publication No. 06-4911

Plan to Attend LFM's Annual Meeting

Barring deep snow, glare ice or extreme cold temperatures, the Lupus Foundation of Minnesota will hold its annual meeting on Tuesday, January 16, 2007 at the Bloomington City Office in the Council Chambers. The meeting is open to all Foundation members and we encourage you to attend to learn more about the Foundation and its mission. This is also an excellent opportunity to meet the board of directors of the Foundation and our staff members. The meeting will start at 5PM, but come early and join us for refreshments beginning at 4:30.

We look forward to having representatives from the lupus research center at the University of Minnesota to share with us about their important work. You may know that the Lupus Foundation of MN has supported research at the Uof M for nearly thirty years. Hear what some of the leading lupus scientists in the country feel about that support!

If you haven't been there before, the Bloomington City Office is located at 1800 West Old Shakopee Road, which is approximately one half mile west of 35W at the 98th Street/Old Shakopee Road exit. The Council chambers are on the ground floor at the north end of the building.

We hope to see you there!



LFM Drops Annual Dues

By Cary Zwolski and John Haffner, LFM STAFF

The Lupus Foundation of Minnesota has recently decided to eliminate annual membership dues in the hope of making the Foundation more available to those in need of our services. The change will primarily affect those living within our service area (Minnesota, North Dakota, and South Dakota) since we will still require membership dues from members living outside this designated area. Although we always encourage and appreciate participation in the Foundation from people all around the world, those outside our service area generally have access to their own local lupus organization, as well.

Several issues prompted the Foundation to come to this decision; the biggest was our intention of increasing our membership. Also, many of the benefits offered to members were becoming available to non-members. It seemed to the Foundation unfair to charge dues for services that no longer required them. After speaking with several other not-for-profit organizations that had good results with eliminating membership dues, the Lupus Foundation of Minnesota board of directors voted to do likewise.

Despite the Foundation's ability to eliminate annual dues, we would not be able to function as an organization or accomplish our mission without the continued support of our members. Therefore we still and always will, appreciate any contribution you are able to make, whether by donating, volunteering, or simply by promoting awareness in the hope of assisting those who have been affected by lupus. Everyone here at the Lupus Foundation of Minnesota would like to thank you for all your past support, and would also like to thank you in advance for your support in the future.

Lupus Nephritis

By John Haffner, LFM Intern

March brings to mind a seasonal transition from spring to winter – although most of the Midwest experiences a different seasonal transition from winter to another winter. Regardless of one’s climatic situation, however, everyone can perceive March 8th as the official World Kidney Day according to the National Kidney Foundation. Nearly 90% of all lupus patients have kidney damage, and in respect to this and March 8th marking World Kidney Day, I would like to emphasize the importance of maintaining healthy kidneys.

Lupus that threatens the kidney (lupus nephritis) causes inflammation in the glomeruli, the parts of the kidney that filter waste from the blood. This leads to the presence of protein in the urine, as well as fluid retention resulting in swelling, generally in the feet and ankles. The type of kidney involvement in lupus ranges from mild to severe, however, all are treatable. Corticosteroids such as Prednisone are typically used to treat lupus nephritis, sometimes combined with immunosuppressive drugs in more severe cases. In the event that lupus causes extensive damage to the kidneys, dialysis or transplantation may be necessary. However, approximately 15,000 kidney transplants are performed each year, with nearly a 98% survival rate, the highest figures compared to any other organ transplantation.

Regardless of the severity of the kidney damage, or if the kidneys have not even been affected by lupus, maintaining good kidney health is important. Should the need for medical treatment of the kidneys arise, consulting with your doctor for the best course of action is obviously necessary. However, even simple lifestyle changes can work wonders for your kidneys.

Diet

Cholesterol – People with chronic kidney disease are also at a greater risk for heart disease. Keeping cholesterol levels down will greatly reduce this risk. That means no more lavish lunch buffets of fried chicken and gravy. Instead substitute with a diet high in plant stanols (margarine and orange juice) and fiber (especially tuna or salmon, walnuts, and oatmeal).

Protein and phosphorous – If your kidneys do not function properly the waste product of protein, urea, may not be filtered out effectively. Make sure you consult your doctor to assess the appropriate amount of protein in your diet. Phosphorous, found in dairy products, beans (ironically enough, including kidney beans), and nuts, also must be filtered from your blood. Keep phosphorus levels down by substituting milk, cheese, and ice cream with non-dairy creamers, cream cheese, and sherbet or sorbet. A high phosphorous level also causes the body to pull calcium from the bones. As you might know, steroid medication can be hard on bones, emphasizing the importance of maintaining a diet low in phosphorous.

Sodium, High Blood Pressure, and Exercise – High blood pressure and kidney disease are directly related. Sodium causes blood pressure to rise, especially in damaged kidneys. Keep blood pressure and sodium levels down by seasoning foods with garlic or onion powder, pepper, lemon juice, or vinegar, instead of salt. Also aerobic exercise such as walking, running, swimming and biking works great for keeping blood pressure down.

Although maintaining a healthy diet can be rather tedious, in accord with World Kidney Day on March 8th, make an effort to improve your kidney health, as well as monitor how lupus may be affecting your kidneys.

Men with Lupus and Antiphospholipid Syndrome

By Michael D. Lockshin, MD

“Why don’t they ever write about me?” I have heard that question so often that it might have occurred to me to volunteer to write something myself, but it did not, so Henrietta Aladjem, editor of *Lupus World*, volunteered me instead.

The reasons “they don’t write about men” are, I think, basically two: 1) thoughtlessness on the part of my colleagues and myself, and 2) there is not a whole lot to say. For the first, I apologize. Sexism, it seems, works in both directions. For the second, most of what is known about male-female differences in lupus or in antiphospholipid syndrome is fairly soft and not very dramatic information.

Only about 10% of lupus patients are men, although the figure may be higher for antiphospholipid syndrome. Antiphospholipid antibody syndrome consists of recurrent blood clots (such as strokes, or clots in the veins of the legs) and, in women, recurrent miscarriages, associated with anticardiolipin antibody or lupus anticoagulant. (Together these antibodies are called antiphospholipid antibodies.) The syndrome can occur either by itself (primary) or in patients with lupus (secondary). About one-third of patients with lupus have the antibody, but only one-tenth to one-fifth have the syndrome.

Studies differ in details, but more studies than not say that men with lupus may have more problems with blood platelets, blood vessel blockage and lung scarring than do women.

Prognosis is about the same in men and women. There may be a higher likelihood of disease in a second family member if the first affected member is male. Even so, the differences between men and women are those of a few percentage points of frequency – 35% low platelets in men, 20-25% in women – that sort of thing, nothing very major.

As far as I can tell, men with antiphospholipid antibody truly differ from women in only two ways: they don’t get pregnant, so they don’t have problems with pregnancy (or with fathering children), and the first doctors they see (in armed forces, in student health centers) do not believe them when they say their positive tests for syphilis must be falsely positive.* As a result they get treated with penicillin more than do women patients.

Because mouse lupus can be made better by taking away female hormones (castrating the mouse) and worse by administering female hormones, there has been much speculation about how “manly” men with lupus and antiphospholipid antibody syndrome really are.

As I see it, they are perfectly normal males. Specific measures of hormone levels in men with lupus have given all sorts of confusing results. (In hormone studies, it is often hard to tell what is the result of illness itself.)

In measures that they and their families can make, men with lupus and men with antiphospholipid antibody syndrome look like normal men; have normal beards, voices, hair patterns,** muscles and other characteristics that I need not mention in polite company; they have normal sexual drive and performance; and they have normal fertility. Homosexuality is no more common among patients with lupus and antiphospholipid antibody syndrome than among the population as a whole.

Furthermore, although some years ago there was a flurry of interest because one clinic saw several men who had both lupus and a rare, feminizing chromosome abnormality known as Klinefelter’s syndrome, most other clinics have not, and the observation has not explained much about male lupus. Bottom line: men with lupus, except for their disease, are pretty normal.

Some doctors have tried to treat female patients with hormones. Current interest in treatment with DHEA is one such attempt. Results are mixed, even in men. The drugs that cause sterility in women also cause sterility in men. While there is much discussion about the wisdom of giving “post-menopausal” estrogen to women, I don’t know of any significant research on giving testosterone to older men or to men who have been treated with cyclophosphamide.

A fair question is: should men and women with these diseases be viewed differently? The answer, in typical doctor double-speak, is both yes and no. No, because as far as we know today, the symptoms and the treatment for both men and women patients are the same. Yes, because any disease heavily weighted to one gender must have an explanation that is important, and yes, because the needs of women and men differ.

Thank you, my patients, and thank you, Mrs. Aladjem, for asking.

* A false positive test for syphilis is characteristic of the antiphospholipid antibody syndrome. Patients with this false positive test do not have syphilis, and the illness has nothing to do with infection by syphilis.

** I have seen even very good doctors mistake hair loss due to lupus for normal male balding.

By Michael D. Lockshin, MD, FACP, Director, Barbara Volcker Center for Women and Rheumatic Disease and Professor of Medicine, Hospital for Specialty Surgery and Cornell University Medical College, New York. Reprinted with permission from *Lupus World*, Vol. 2, No. 1.

Reflections of *Camp Sunshine 2006*

Timberly Williams

Nestled along the shores of beautiful Lake Sebago in the state of Maine, Camp Sunshine provides respite, support, joy and – perhaps most importantly – **hope** to children with chronic illnesses and their immediate families. The year-round program is free of charge, includes 24-hour on-site medical and psychosocial support and camp goers can attend at various stages of illness. Bereavement support groups are also offered for families who have lost children to chronic illness. Thanks to our devoted supporters, the Lupus Foundation of MN has been able to participate by sending campers and their families to Camp Sunshine.

I volunteered at the camp during lupus week – and witnessed firsthand some creative ideas that will hopefully allow LFM to reach out to more people in different ways. The three volunteers with me on the adventure were: Jeri Hunt (*lupus patient and retired school teacher*), Sandy Odden (*Jeri's best friend of 35 years and also a school teacher*) and Tenisha Williams (*my 16 year old niece*).

I wish that this camp had been available when I was a child! It's kid-friendly *and* perfect for both healthy and chronically ill children. The best part is that the volunteers, staff and supporters are impacting the lives of children with chronic illness.

If you are interested in learning more about Camp Sunshine, visit www.campsunshine.org

Or visit the *Support Page* on the LFM website, www.lupusmn.org

Jeri Hunt

Something felt different at home when I returned from lupus week at Camp Sunshine. My cats punished me for my absence by acting aloof; and the two days of me sleeping didn't come as a surprise, as I have lupus myself. By the third day, I had figured it out. I didn't want to *be* home. This 54 year old gal still wanted to be at camp!

When I was there, I worked with the 13-15 year olds (*most from New York*), which was interesting for me because I taught elementary-aged children for 30 years. My group was a mixture of kids who have Lupus and kids who don't (*siblings, friends*). I felt lucky to experience both perspectives.

One of my favorite times was sitting in a paddle boat on Sebago Lake with Jess (*15 year old boy*) and Marnea (*14 year old girl*). I asked them about their lupus. They weren't very talkative until I told them that I **also** have the disease. Then the high fives flew everywhere and they opened up to me like old friends who share a common thread that runs through each of our lives (*actually, it does*). We talked about not always wanting to tell people about our illness because of the way they might treat us. We discussed our hopes and dreams, camp, and how we just wanted to relax and have fun.

I spent a lot of time with Paige (*14 year old girl – wise beyond her years*), whose sister has Lupus. Seeing the illness through her eyes gave me a new perspective on how lupus affects my siblings, friends, and daughter. Paige and I have become email buddies.

I learned more about lupus, children who have it, and my outlook on my own lupus. I watched the campers laugh, dance and just be silly.

Yes, I wish I were at camp again. But now, my big wish is that next year I'll be taking some of you with me...

Tenisha Williams

This year was the first time I ever heard about Camp Sunshine. When I signed up to be a volunteer counselor earlier this year, I had no idea what to expect; I just knew that I'd be going for lupus week. I thought that I had prepared myself to spend time with kids with lupus and their families. When I arrived, I quickly learned that the camp is a place for families to socialize and have fun (*among the other aspects*). It seemed to be somewhat of a "reunion" for most families; some of them schedule it in as an annual event and have generated a number of friends from other families. During a short week in August, I made friends and gained a new understanding about Lupus. I remember being with an older camper during "free time" while she overcame her fear of heights by climbing a rock wall for the first time in her life. I would compare her experience to my own throughout the duration of the camp.

Sandy Odden

As I begin my 31st year of teaching elementary-age children, the superintendent of the school district is strongly advocating (*and implementing*) the theme "A Sense of Belonging" for this school year. That, I believe is the key to success in any system – whether it's a school district, corporation / local business, place of worship, camp or anything else.

At Camp Sunshine, I observed the staff and volunteers diligently working to make the campers and families feel welcome. Every child with lupus, their siblings and other family members, were given the opportunity to be part of the group. Most of them seemed to enjoy the many activities and interaction with others in this beautiful facility.

Carmen, a woman whose son has lupus, shed many tears of joy and that sense of belonging throughout the week, which was heartwarming. Her tears, also her smiles, said it all – even though she found it difficult to express herself in English. Luis greeted me daily with a big smile and a handshake, so pleased to be at Camp Sunshine with his wife and three of their five children. I'm sure they'll be back next year, hopefully with their entire family.

It was great watching kids be kids. Children with lupus were not singled out, except for wearing a small indicator on their name tags so that volunteers could be attentive to their needs. I especially appreciate having learned more about 13-15 year olds, soaking up the East coast culture and listening to various dialects (*of which I have no grasp, ya sure!*) Spending a week with my very special friend of 35 years and better understanding the way lupus affects her, made my experience at Camp Sunshine complete.

"It was great watching kids be kids..."

— Sandy Odden



LEFT TO RIGHT
Timberly, Tenisha, Sandy and Jeri

"I wish that this camp was available when I was a child!"

— Timberly Williams

"We discussed our hopes and dreams..."

— Jeri Hunt

"I made friends..."

— Tenisha Williams

"Children with lupus were not singled out."

— Sandy Odden

If you are interested in learning more about **Camp Sunshine**, visit www.campsunshine.org

OR

Visit the *Support Page* on the LFM website, www.lupusmn.org

Support Group Information

Support groups can contribute to the wellness of a lupus patient. Our support system includes people available for telephone discussions or monthly meetings conducted by volunteer facilitators. We encourage you to take an active part in one of the following groups.

Twin Cities Area Groups:

BLOOMINGTON –

Christ the King Lutheran Church
86th & Fremont Ave. S
Third Monday, 7:00 - 8:30 p.m.
Judy Johnson, (952) 831-4722 or
Arlene Knutson, (952) 881-8558

BLOOMINGTON –

Healing Through Art and Expression

LFM Office: The Atrium, Suite 135
2626 E 82nd St.
Meeting times vary.
Call Bertha Edwards, (952) 707-1299

BLOOMINGTON –

Young Adults

LFM Office: The Atrium, Suite 135
2626 East 82nd St.
Call for dates and times.
Melinda Sykora, (612) 437-1180 or
Jeri Hunt, (651) 481-8588 / hjh55126@aol.com

INVER GROVE HEIGHTS –

Khoury's, 6588 Cahill Avenue East
First Tuesday, 6:00 p.m.
Mary Joyce, (651) 739-4919 or
Nancy Palmer, (651) 894-9689

MINNEAPOLIS –

Sabathani Community Center
310 East 38th Street
First Tuesday, 7:00 - 8:30 p.m.
Check front desk for conference room number.
Angela Williams, (612) 529-2753 or
(612) 242-8731, Please call to RSVP

MINNEAPOLIS –

Southdale Resource Library
7001 York Ave S, Edina, MN 55435
Meeting times vary.
Benita Taylor, (952) 829-8063

SAINT LOUIS PARK –

Park Nicollet Medical Center
7th Floor West Conf. Room
(Co-sponsored by Arthritis Center)
Third Tuesday, 7:00 - 8:30 p.m.
Joyce Johnson, (612) 721-5403 or
Deb Turner, (763) 585-0342 / debt@aol.com

Outside Metro Area Groups:

ALEXANDRIA – Douglas County

Hospital Board Room
Karla Lysen, (320) 634-0276

DULUTH – Saint Mary's Hospital,

Oncology Classroom (4th Street Entrance)
Last Wednesday, 7:00 p.m.
No summer groups (July - October)
Kathleen Pearson, (218) 722-0881 / kateQi@aol.com

MANKATO – Call for meeting location.

Third Thursday, 2:00 p.m. and 7:00 p.m.
No summer meetings.
Nadene Sandon, (507) 345-8950 or
Diane Beyer, (507) 388-8991

ROCHESTER – Meadow Lake Senior Living Group

22 45th Avenue NW
First Saturday, 9:30 - 11:30 a.m.
No summer meetings.
Carolyn Hyland, (507) 292-0945 /
curelupus@charter.net or
Judy Nishimura, (507) 282-2499

ST. CLOUD – Health Partners

1245 15th St. North
Fourth Thursday, 2:00 - 3:30 p.m.
Karen David, (320) 393-4206

ST. PETER – Country Kitchen

Third Thursday, 2:00 p.m.
Sue Schott, (507) 246-5247

WILLMAR – McMillan's Restaurant

Last Thursday, 2:00 p.m.
Janelle Joneson, (320) 796-5119

Out of State Groups:

BISMARCK, ND – Elks Lodge

Second Thursday, 12:00 p.m.
Dave & Jan Jundt, (701) 258-6345

PIERRE, SD – Countryside Hospice, Inc.

200 E Dakota, Suite 100
First Thursday, 7:00 p.m.
Elaine Konechne, (605) 945-0827

RAPID CITY, SD – Black Hills Arthritis

Association Office, Midtown Plaza:
429 Kansas City Street
Third Saturday, 9:00 - 11:00 a.m.
Nickie Steinback, (605) 721-2864 or
lupus@rushmore.com

SUPPORT AVAILABLE VIA TELEPHONE...

Each volunteer has personal interest in and/or experience with lupus. It's nice to have a listening ear, as physically reaching a group isn't always possible.

Big Lake: Lorna Brown, (763) 263-5861 or
landd@yahoo.com

Brainerd: Barb Worms, (218) 829-8535 or
bworms@charter.net or
Yvonne Hjelm, (218) 829-3032

Cloquet: Susan Appleton, (218) 628-1659

Dickinson, ND: Alena Praus, (701) 483-9454

Duluth: Kate Pearson, (218) 722-0881

Eau Claire, WI: Allison Claussen, (715) 723-4362

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Hutchinson: Sheila Mogard, (320) 587-6829

International Falls: Kitty Ewald, (218) 285-7142

Maple Grove: Sandi Olson, (763) 550-1663

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Rochester: Carolyn Hyland, (507) 292-0945 or
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Sioux Falls, SD: Sioux Valley Healthformation,
(605) 333-4444

Twin Cities:

Patty Krageland, (651) 699-2332 or
Patricia Walsh, (952) 929-3547 or
walsh21@msn.com

Get SPECIFIC needs met!

TWIN CITIES AREA

Habla Espanol

Sarys Gomez-Lira, (651) 735-0566

Habla Espanol/English:

For Men and Women with Lupus
Gustavo Taberna, (651) 707-7707 or
gtaberna@lupusmn.org

Parents of Children with Lupus:

Cary Zwolski, (651) 784-7318



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Thank you to all of our faithful contributors who use the pickup service to make donations to the Lupus Foundation of MN! **As a helpful reminder, we aren't able to take your computer monitors or TV's bigger than 25" or those having turn style knobs, and no console TV's, please.** Again, we're grateful for your generous donations!

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Lupus News

Soup's on!

Slow Cooker Vegetable Chili

This is a zesty, hearty recipe that's loaded with veggies! Garnish with light sour cream and/or cheese (if desired) and serve with herb toast. Use any type of beans you like!

Calories: **193 per serving**
Calories from Fat: **N/A**
Total Fat: **2.63 g**
Total Carbohydrate: **35 g**
Protein: **7.48 g**

Ingredients

- 1 (28 ounce) can whole peeled tomatoes with juice
- 1 (15 ounce) can garbanzo beans (chickpeas), drained
- 2 zucchini, thinly sliced
- 1 onion, chopped
- 2 carrots, sliced
- 2 stalks celery, sliced
- 1 red bell pepper, chopped
- 1/3 cup chili powder (or your favorite prepared chili mix)
- 1 (4 ounce) can chopped green chili peppers
- 2 cloves garlic, minced
- 1 tablespoon dried oregano
- 2 teaspoons ground cumin
- 1 teaspoon salt

Directions

1. In a slow cooker, combine the tomatoes, garbanzo beans, zucchini, onion, carrots, celery, red bell pepper, green bell pepper, chili powder, green chili peppers, garlic, oregano, cumin and salt.
2. Cover and cook on low for 6 to 8 hours OR on high for 3 to 4 hours.

Serves 6 to 8

2007

Schedule of Events

January

18 monthly Support Group Meetings

10 WEDNESDAY, 11:30 AM:
Buddy Lunch, LFM office,
Please call to RSVP

16 TUESDAY, 5:00 PM:
Lupus Foundation Annual Meeting,
Bloomington City Hall

26-28 FRIDAY – SUNDAY:
Women's Expo,
Minneapolis Convention Center
Friday: Noon to 8 PM
Saturday/Sunday: 10 AM to 6 PM

February

18 monthly Support Group Meetings

7 WEDNESDAY, 11:30 AM:
New Client Orientation,
LFM office, Please call to RSVP

March

18 monthly Support Group Meetings

7 WEDNESDAY, 11:30 AM:
Buddy Lunch, LFM office,
Please call to RSVP

20 TUESDAY, 5:00 PM:
Lupus Foundation Board Meeting,
Bloomington City Hall

April

18 monthly Support Group Meetings

MINNESOTA

The William Flies family dedicates this issue of the Minnesota Lupus News to the memory of their daughter Murette. Murette was committed to educating others about this disease. We honor her for her determination to make a difference in the world. We miss her dedication, her resolve... and her smile.

Minnesota Lupus News is published quarterly by the Lupus Foundation of Minnesota. Send change of address notification at least 30 days prior to effective date, including both old and new addresses. The Lupus Foundation's phone numbers are **952-746-5151** and **800-645-1131**. Our web address is www.lupusmn.org