



Lupus News

Changing with the Changes: A Full, Purposeful Life with Lupus



Ruth Stricker Dayton

Ruth Stricker, 75, lives one of those lives we'd all like to have. She's gorgeous, intelligent, and deeply passionate about causes she supports. She and husband Bruce Dayton, of the Dayton's department store family, have set arts-loving hearts aglow with their donations of Asian art to the Minneapolis Institute of Arts. In 1985, she founded The Marsh, a Center for Balance and Fitness in Minnetonka, which was the culmination of years of study in wholistic medicine, fitness, and Eastern philosophy. And, as if that weren't enough, she's also a mother and grandmother, and sits on the boards of three international organizations.

Ruth Stricker doesn't have time for lupus. But she's lived with it for the past 35 years. "When asked how he could be so prolific, George Bernard Shaw once said, 'At some point, I learned to happen to my days, rather than let them happen to me,'" quotes Stricker, summing up her attitude toward lupus.

She doesn't take it lying down. "I consider myself a well person in a diseased body. I could have let myself become a victim. 'Oh, that poor Ruth. She has lupus. We better help her.' But I'm not a victim. I'm so much more of a person than I would've been if I hadn't gone through my experiences."

Fitness on the Cutting Edge

Stricker grew up in Windom, Minnesota, the child of a Presbyterian minister and his wife. Even as a child, she was active and enjoyed sports. So it wasn't a stretch for her

to major in physical education at Macalester College. Yet like her father, her brother and nine uncles, she also showed a keen interest in religious studies.

The twin interests—fitness and religion—pursued Stricker after graduation, when she and her first husband moved to Massachusetts. It was here she encountered and then immersed herself in the works of fitness pioneer Bonnie Prudden, who'd helped launch the President's Council on Youth Fitness in the 1950s. Stricker also became aware of the mind-body philosophy embodied in practices like yoga, meditation, and tai chi. She was beginning to realize that fitness was more than tight pecs and abs. It was about happy hearts and minds too.

When Stricker returned to Minnesota, she implemented these new concepts in a series of fitness classes taught around the Twin Cities Metro. These were years of hustle and bustle. She shuttled between exercise groups. She talked to organizations about the mind-body connection. She met with students, and then raced home to look after a house and two growing children.

She was invested in fitness, and actually making a difference in her community. But just as her career was hitting its stride, the world shifted under her.

The Lupus Diagnosis

The summer of 1975, Stricker was working at a summer camp for girls. She took 16 16-year-old girls on a backpacking trip to Colorado. It was the perfect summer outing, if a little exhausting. But no one ever said looking after 16 girls and charging the rapids on a rubber raft would be easy. However, none of that busyness accounted for the blotches covering her body or the flu-like symptoms that seemed to mysteriously come and go.

Back in Minnesota, Stricker made an appointment to see a dermatologist. The dermatologist was the one who delivered the life-altering words. "Uh-oh," he said to her. "I think you have lupus." Lupus? Stricker didn't know how to process the news. She exercised. She ate right. Heck, she had even devoted her career to healthy living. How could she have a chronic disease?

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By January 1976, systemic lupus had kicked in and Stricker was staring down the ugly statistics. "The medical journals at the time were really morbid. They'd say things like no one lives more than five years with lupus. That kind of thing," she says. Her doctors offered advice, but not the advice she wanted—or needed—to hear. "They told me I had a progressive disease and that I'd be looking at a pain clinic. Another doctor told me I should just go to bed for two to four months."

But Stricker didn't go to bed. She didn't curl up in a ball and withdraw from the world, though the temptation was there. "Eventually I had this conversation with myself," she says. "I said, well, I can't depend on God to save me. The Lord helps those who help themselves, right? I can't depend on the doctors to save me. So, I guess I have to take control of my life."

By this time, Stricker's first marriage had come to an end. The breakup was amicable, but now she was a single mother rearing two children, on top of handling a chronic disease. Yet what had her training in mind-body conditioning taught her if not to take control of her life, in good health and bad? Sickness was just another point on the health continuum.

"I went through all the anger and denial. But once I had my life squared away, and my death squared away, I was given permission to take risks. Because so what? I already had lupus. It was as if someone was up there saying, 'You go, Ruth. Just fly,'" she says, and ten years after her diagnosis she opened The Marsh.

Thriving in the Company of Lupus

Stricker dreamed up The Marsh on the back of an envelope. She conceived a fitness center that would embody a wholistic approach to health, which included situating the 67,000-square-foot facility on the edge of a nature preserve. In the 1990s, Stricker had spearheaded research on the question of the mind-body connection to well-being.

"My premise was that if you are in your favorite sweatshirt, spending time with your favorite person, walking in your favorite woods, the benefits would be much greater psychologically than if you were on a treadmill, in a sterile white room, gritting your teeth and saying, 'This must be good for me.' And that's what we found," says Stricker who has built that ethos into every room of her center.

The Marsh invites young and old, sick and well, rock-solid athletes and casual exercisers, members and non-members, to its Minnetonka address. The facility houses swimming pools, hot tubs, a Pilates studio, exercise rooms, and an indoor-outdoor walking track, alongside meeting rooms, a café and sit-down restaurant, art gallery, and gift store.

A lot has changed since Stricker received her diagnosis in 1975. For one thing, there's more research on lupus and more treatment options. And Stricker's life has changed, too. She's gotten older, yes, but also a lot wiser about living well with chronic illness.

"You have to learn the dimensions of lupus," she advises. "This is hard, because at first you don't know what is and what isn't lupus. You could have lupus, cancer, the flu. You don't know. So, knowing the dimensions of lupus is important."

Stricker is wearing more hats these days. She is active at her alma mater, recently dedicating a building on the Macalester campus. She has speaking engagements and interview requests. She has children, grandchildren, and her husband Bruce. And there's still her lupus to consider. Stricker's answer to a hectic schedule is blue sky—free time and wiggle room. "If I don't make it into the office by eleven, it's not because I'm sitting home watching soaps," she jokes. "It's because I couldn't make it in earlier. Sometimes it can take an hour before I can hold a hairdryer."

Stricker deals with pain by staying in the present moment, something she picked up from her study of Eastern religions. "The mind is either dragging in the past or worrying about the future. But the body is always in the present moment. If you can bring your mind where your body is, that's peace, that's wellness." Stricker practices meditation and tai chi to bring her mind and body into alignment.

Another important facet of wellness, according to Stricker, is socialization. Getting out of your head and heading into the world. In a word, mingling. Stricker calls it 'energy exchange.' "Exercise is good for socialization because when you exercise you open up. I saw this when I taught classes. People would stick around after my classes just to talk about life, the ups and downs."



"The mind is either dragging in the past or worrying about the future. But the body is always in the present moment. If you can bring your mind where your body is, that's peace, that's wellness."

— Ruth Stricker

She also stresses a positive attitude. No, she can't cure her lupus. No, she can't function 100 percent every day. But that doesn't matter. No one can function at 100 percent every day. "The thing is to make peace with constants, so you can change with the change, like a cork floating on the water. That's called resilience, the ability to spring back," Stricker says, as she has said so often to students and friends dealing with their own unalterable conditions of life. "My big theme is you can't wait for a cure. So you better make the best of what you have; and even more, do the best you can to live a full, purposeful life."

From the Desk of the President

By Jennifer Monroe, President

Thank you for picking up the spring edition of *Lupus News*. This edition focuses on interviews and articles with a variety of individuals *sharing strategies for successfully living one's life with lupus*.

The topic couldn't be exemplified any better than in the revealing cover interview with Ruth Stricker. As founder of **The Marsh: A Center for Balance and Fitness** in Minnetonka, Stricker has found significant success raising a family, running a business and advocating for others (*The Marsh serves over 35,000 individuals a year*). She has accomplished this by inspiring, challenging, educating, and promoting good health and healthy practices both locally and globally.

As a pioneer and spokesperson for the integrative approach to health and wellness, Stricker has been the recipient of numerous national honors including the SHAPE magazine IDEA Award, The Alex Szekely Humanitarian Award from the International SPA Association, and she was

named a Healthy American Fitness Leader by The President's Council on Physical Fitness. She even co-sponsored a study with the University of Massachusetts Medical School which led to a series of published academic abstracts and papers on the scientific evidence regarding mind-body interactions.

This spring, The Marsh will celebrate its 25th anniversary of offering education, training and practice towards a holistic approach to health. This year will also approach the 35th anniversary of Stricker's own diagnosis with lupus.

We are pleased to share with you the personal insights and philosophies—as well as some of the significant contributions to the health of the greater community—Stricker has contributed both as an individual and a businesswoman in this edition.



ABOUT THE PERFORMANCE

Tony Award-winning and Pulitzer-finalist M. Butterfly traces lines of race, gender and power through love and deception. French diplomat Rene Gallimard is dazzled by "the perfect woman," Song Liling, a performer in the Peking opera. Yet as he seeks power over her, he finds far more than the submissive leading lady he wanted. When M. Butterfly premiered on Broadway, The New York Times hailed it as "a visionary work that bridges the history and culture of two worlds."



THE LUPUS FOUNDATION OF MINNESOTA

Annual Meeting & Spring Evening Fundraiser

TUESDAY, MAY 18

5:00 p.m. – Annual Meeting

Spill the Wine Restaurant

5:30 - 7:00 p.m.

- Cocktails and Hors d'oeuvres
- Corporate Contributor Award Presentation: Sterling State Bank
- Silent Auction

Spill the Wine Restaurant

7:30 p.m. – Performance of M. Butterfly

Guthrie Theater

COST

\$50 per person includes M. Butterfly ticket (\$29 value), private reception at Spill the Wine with cocktail/glass of wine and hors d'oeuvres, and parking (lot is just a few short blocks from the Guthrie)

RSVP BY APRIL 19

Call Sara at LFM at 952-746-5151 or email to sotto@lupusmn.org to reserve your tickets. A confirmation letter with parking and driving directions will be mailed after your order is received.

Book Excerpt: Chronic Control

By Sara Gorman

*The following is an excerpt from Sara Gorman's newly published book, **Despite Lupus: How to Live Well with a Chronic Illness**. In this selection from chapter two, titled "Chronic Control," Ms. Gorman talks of the need to find outlets for the loss of control one has experienced due to the effects of living with a chronic illness. Incorporating order, method, routine and ritual into one's daily life can help, and should be considered an integral step to living well.*

Life with a chronic illness isn't easy. It takes patience, understanding, and courage. It requires that you make decisions that you might not want to make, and it necessitates changes in areas of your life that you don't want to alter.

The consequences of having lupus extend to almost every aspect of your life, so it's tempting to convince yourself that the effects of your disease are too overwhelming to combat, much less overcome. You think that because you have this debilitating, overpowering illness, you no longer have any control over how healthy or happy you could be. You're at the mercy of the disease and, sadly, you believe there's nothing you can do about it. How unmotivated you must be to improve your hopeless situation!

At present, your resistance and even indifference to making life better is understandable. Nothing you've tried thus far has worked permanently, and you have little faith that your efforts will ever pay off. You decide once and for all that life will never be as good as it once was, so you stop trying to make it anything more than it is. Why continue to exhaust yourself when you'll just end up disappointed?

Disappointments in life are bound to occur, you admit, but when it's your own body letting you down, refusing to bounce back the way you expect it to, the way it should, the feeling of failure is devastating. One setback after another has worn you down, and you're fed up with the compromises.

You've been hampered and hindered by lupus long enough, carrying more baggage at your age than you ever thought possible. You're negative and apathetic, no longer enjoying the things you do or the people you're around. Struggling day after day, you've grown resentful and jaded. You are unwilling to work on the state of your health because no positive results ever come of it.

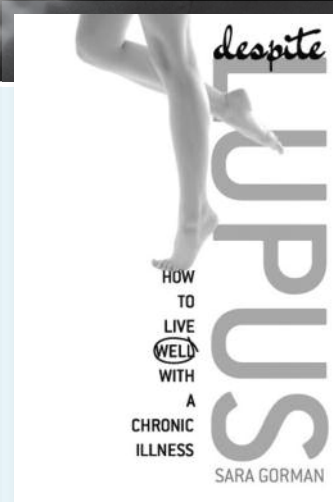
I remember being in this vulnerable, precarious state all too well: fighting the battle and never winning; concluding that the easiest way out is to give up on finding a way out. If you don't make the attempt, you can't be considered a failure, right?

Wrong! You are more responsible for your health and well-being than ever before, and the effort you exert can and will greatly affect the outcome. Shirking this responsibility is the worst offense you can commit against yourself, and that's true whether or not you have a chronic illness.

We are the gate-keepers of our own bodies and minds, the most influential executives in determining the state of our physical and mental health. We have an obligation and a responsibility to take care of ourselves, inside and out, despite the many external factors that will try and come between us and healthful decisions. What we eat, how active we are, if and when we allow stress, change and hardship to affect us are all within our command.

Clearly, the choices aren't always easy, but no one is in a better position to make the right ones than you are. You know your body better than anyone – what works, what doesn't, what helps, and what hinders.

Let's take the pain caused by lupus, for example. While you may not be able to recite the scientific, root explanation using advanced, technical, medical jargon, you are well equipped to identify where you hurt, the severity of the pain, (relative to other experiences you've had) and, if you are particularly perceptive, you can probably figure out what's worsening or lessening the pain. You have the ability to determine the internal and external factors that are affecting you and your body, not to cure the disease, but to make your life better.



Sara Gorman, author of *Despite Lupus: How to Live Well with a Chronic Illness*.

Once you focus your efforts on eliminating (or capitalizing on) those factors which you've identified, you can personally, and drastically, improve the state of your physical and/or mental health.

Let me stress – I'm not proposing to eliminate lupus from your life; I'm proposing a way of life with lupus that is better. An integral part of the path to wellness means becoming attuned to and staying in touch with your body so that you can take an active part in pursuing a happy, healthy lifestyle, despite your disease.

Even in the seemingly autocratic world of lupus, where the disease seems to dictate everything you do or feel, you have the golden opportunity to influence, participate in, and even control, the path your life takes. Brute force, as you'll learn in the next chapter, rarely works. But strategic, purposeful, insightful thoughts and actions will bring you the results you want to pursue the pain-free life you're after.

Once your mind and body accept the onus of living a healthy lifestyle, the choices you make will follow, keeping you on the permanent path to wellness.

*Ms. Gorman was diagnosed in 2001 with systemic lupus at the age of 26. The steps she took to regain the health and wellness she'd lost due to lupus are outlined in her book, *Despite Lupus: How to Live Well with a Chronic Illness*. Letting go of her career, postponing plans for pregnancy, and cutting off her hair (or what she had left) are just a few of the monumental, courageous steps she took to reach her goal of living well, despite lupus.*

A native of Indiana and graduate of the University of Notre Dame, Ms. Gorman resides in Alexandria, Virginia with her husband and daughter.

Lupus with a Preventative Focus

By Gustavo Taberna, LFM Community Outreach Coordinator

When I was diagnosed with lupus in 2002, my first question was “what is that?” I soon found out what lupus was for me. I experienced flares involving my lungs, heart, kidneys, liver, bones, eyes, etc.

With each flare, new challenges and uncertainties appeared. During periods of remission, I lived under the rules of fear asking my doctors how I could make the remission last? I lived with the anxiety that even if I was motionless my lupus would flare.

After kidney failure in 2008, I asked myself some very serious questions like “Do I wait until something else happens or change my strategy and push my doctors to focus on other medical issues that have been put on hold?” But when I spoke with my doctors, they assured me that they were doing everything possible. I accepted their word with no argument.

In February 2009, I had a massive heart attack that required a triple bypass. I questioned why warning signs were not discovered. There was now reason for arguing. I was tired of worrying about my next flare and which organ might be involved.

I knew it was impossible to prevent everything, but my medical charts contained a lot of information about my life with lupus and I knew there were many medical issues waiting that should be addressed. It was time to address them. It was time for a preventative focus. No more waiting.

While in the hospital recouping after surgery, I had time to think and develop a game plan around my medical care. My *preventative approach* focused on partnering with my medical team by actively addressing the variety of issues that affect my life with lupus.

My first step was to meet with each member of the medical team and present my plan. For me **“preventative” centered on four aspects of my medical care:**

1. Preventing flares: Review potential medical issues that haven’t been addressed because of my more pressing medical problems. For me, some of these medical issues were kidney stones, gall bladder problems and a hernia. These potential problems, if left to worsen, may lead to a flare, hospitalization and/or surgery.

2. Quality of Life Issues: Review problems that could become progressive and/or create damage if left unaddressed. For example, after a hip replacement in 2007, it was discovered that the length of my left leg was one centimeter longer than the right. This imbalance creates a limp which causes increasing pain in my knee and foot. If left unattended, this issue poses the risk of further damage making surgery inevitable.

3. Explore what we don’t know: Evaluate issues that were treated but weren’t made a priority because of other pressing issues. For example: multiple blood clots – what is their origin? The goal is to find out what is causing the clots in order to prevent flares, hospitalization or emergencies.

4. Here and now: Reporting changes and symptoms that have happened since the last appointment and evaluate their impact. For example, after my heart attack, I was placed on a medication, diet and exercise regimen designed to help recover systems that were affected by the malfunction of my heart.

This game plan has structured our appointments and allows us to work in partnership. More than ever we are taking advantage of every minute.

Below are tips for taking a preventative focus:

- **Take, Keep and Bring Notes to Appointments:** Be aware of your active and inactive issues with organs and systems. Initiate the conversation; do not wait for the doctor to bring it up.
- **Do Not Assume:** Always ask, even if you think you know.
- **Do Your Part:** You are seeing a trained professional, but they need your help. No one knows your body and life with lupus better than you
- **Bring an Advocate:** Put them to work, make sure they take notes, are able to remind you of information, etc.
- **Be Active:** This is a plan designed to be put in action. Participate actively. Work for your health. Make a decision, be consistent and insist. This is your life.

If you have any questions or comments about this article, please contact Lupus Foundation of Minnesota Client Services at 952-746-5151 or 800-645-1131.

Lupus: Beyond the Medical Definition

What Does It Really FEEL Like?

Many have heard of lupus, but understanding the meaning of lupus is more complicated. A clinical definition is available and it does create some insight; however that information exists in a flurry of medical laden terminology.

For those diagnosed, medical terminology doesn’t explain the physical sensations and the reality of living with lupus. In order to create awareness and allow those not diagnosed to gain a sense of what lupus is like, we asked the question: What does having lupus feel like?

Responses are highly individual and highlight the fact that this unpredictable chronic disease impacts each individual differently.

If someone you know has lupus, ask them what it feels like. Their responses may open a dialog and provide you with the opportunity to better understand.

Shane: Diagnosed 1995

Lupus is never knowing what is next to happen to your body. It is a club that very few of us men are in. High and low points to the steady in-between flare ups, it is enough to drive anyone nuts. In short, buckle up, hang on, the ride is one of a kind.

Susan: Diagnosed 2004

It was a couple of days before Thanksgiving and the diagnosis was lupus. Of all the symptoms lupus can cause, fatigue is one of the hardest for me to deal with. My whole body feels heavy, and in the morning I have to lift my Velcro body off my Velcro bed. Some days are better than others and I try to get back to living again. But it is constant fatigue and exhaustion.

Julie: Diagnosed 2005

Being diagnosed has been a humbling experience. I feel like I have the flu most of the time, with a rash, swollen eyes, and various other random symptoms. Emotionally I feel stronger than ever, and can even appreciate the bad days (most of the time).

Mary: Suspected diagnosis, but unconfirmed

Lupus feels frustrating. The aches and fatigue are hard to put into words to even explain to the doctors. The invisibility to others makes you feel unbelievably. The doctors are always trying to look for other reasons why you have symptoms. It is frustrating to go through all the hassle of trying to get a diagnosis. Trying out the different drugs and dealing with the side effects are a pain. Friends and family don't know what lupus is. I have a sister with MS and they know what that is, but no one seems to know what lupus is. If you don't have the butterfly rash on your face, they don't think you have lupus.

Steve: Diagnosed 2006

What does it feel like having Lupus? That depends on which day you ask me. Today, I feel “ok” which is like getting a ‘C’ on a test exam. Aches and fatigue aside, I had an ‘A’ on my health report card yesterday. Tomorrow will be different too.

How about sharing with LFM and others the ways you’ve described lupus or how lupus physically feels to you. Log on to our Facebook page and look for the discussion topic.

Getting the Word Out:

The "Could I Have Lupus?" National Ad Campaign Links to Local Resources

By Britt Aamodt

You may have seen the ads waiting at your bus shelter, a billboard showing 42-year-old Ladan next to the words: "Headaches. Swelling. I want answers. Could I have lupus?" Or you've opened your web browser, ready to click into your email when your attention is caught by an ad featuring Wendy, age 35, next to a list of symptoms: "hair loss, joint pains, very tired."

The ads are the result of a unique collaboration between the Office on Women's Health (OWH), the Ad Council and other partners to get the word out about lupus. The idea behind the campaign is to educate women who are suffering from lupus symptoms, informing them that support and answers are available.

But why the need to get the word out? An estimated 161,000 to 322,000 adults in the U.S. are known to have lupus, while many others may have symptoms but lack an accurate diagnosis. That's a lot of people. A 2009 Ad Council survey found that 80 percent of women know next to nothing about lupus. It can take an individual, on average, three to four doctor visits to receive an accurate diagnosis.

An Early Diagnosis—Getting an early diagnosis can make a world of difference to someone with lupus. Just ask Frances Ashe-Goins. Ashe-Goins is a registered nurse and health educator at the Office on Women's Health. In 1999, her niece fell ill.

"The doctors didn't know what she had," says Ashe-Goins. "They thought she might have HIV. Then they thought she had some form of cancer, then pneumonia.

Just a few short months later, her niece died in July 1999. She was 27. Around the same time, another OWH staff person also had a relative dealing with late-diagnosis lupus.

"In one office to have two people whose family members had been diagnosed with lupus? That was out of ordinary," says Ashe-Goins, who did what her nurse's training had taught her to do. She researched lupus. Her quest put her in touch with the Lupus Foundation of America and together they developed an employee education program. They rolled out the program in a room with an 800-person seating capacity. "But we had so many people, there was standing room only," remembers Ashe-Goins, "and these were only employees. We realized there was a huge interest...everybody seemed to know someone with lupus, but no one had a clue what it was."

Awareness Through Advertising—The "Could I Have Lupus Campaign?" was born out of that interest and a need to reach and educate a national audience about lupus and

its treatment, specifically minority women between the ages of 15 and 44. Lupus is two- to three-times more common among African American, Latino, Asian, and Native American women of child-bearing age.

The television, radio, web, print and billboard ads show minority women like Ladan, Wendy and Artranese, real women living with lupus, not actors. The ads describe lupus symptoms, and direct individuals who want more information to a toll free number (800-994-9662) and dedicated website (www.couldihavelupus.gov).

The three-year campaign began in 2008. But the official launch didn't take place until March 2009. "I would also say that, in general, public awareness has been building over the last year or two. The ad campaign has definitely played a key role in elevating lupus on the nation's public health agenda," says Maggie Maloney, spokesperson for the LFA.

Phone calls are not the only means of measuring the impact of the "Could I Have Lupus?" campaign. "Since March 31 of last year, the campaign has received \$17 million in donated media," says Ashe-Goins. "To put that into context, an Ad Council campaign typically receives about \$7 million per quarter. So, we're way over that."

Vital Link to Local Resources—The ad campaign is only a first step. The toll free number on all the ads links individuals to the OWH and a network of resources, including the Lupus Foundation of Minnesota, which is the only organization dedicated

to providing consultation, workshops, support groups and other direct services to individuals throughout Minnesota.

The "Could I Have Lupus?" website expands the idea of community to the virtual world. The website not only provides facts and a list of resources but also a discussion forum and diary tab. Individuals can post questions and receive answers from other women from around the country. The diary tab allows women to share their personal stories of living with lupus.

Ashe-Goins says she plans to keep the website running even after the ad campaign concludes. "It's important for people to have a reliable source of information, and to take action when they have lupus symptoms. Because a little bit of information can lead to positive action and healthy outcomes."



A Portion of the Spanish and English Campaign Ads

12th Annual
LUPUS GOLF CLASSIC
Wednesday, July 7
StoneRidge Golf Club, Stillwater

10:00 a.m. Registration
10:30 a.m. Driving Range Opens
One-on-One Instruction
with PGA Professional
Kevin Lucken
12:00 noon Shotgun Start
(Box lunch on carts)
5:00 p.m. Social Hour
6:00 p.m. Dinner, Auction & Awards

July 7th Lupus Golf Classic Benefits Research

Join the Lupus Foundation of Minnesota for the 12th Annual Lupus Golf Classic at StoneRidge Golf Club in Stillwater on Wednesday, July 7. The (scramble format) tournament will begin promptly at 12 Noon with a shotgun start and concludes with dinner program and awards following the 18 holes.

Golf participants can look forward to a wonderful tournament experience including a fun-filled day of golf, great dinner, course games, and finally an enhanced dinner program on the "Big Screen," says LFM President Jennifer Monroe.

Proceeds from this annual fundraising event go entirely to fund lupus research. This event to date has raised over \$425,000.

"We are appreciative of GLS Companies who took a generous leap to start us off on the right foot with a significant title sponsorship," said Monroe, "but we still need your help to continue to raise needed funds to support this important cause."

For more information about this event, sponsorship opportunities or ways to get involved, contact Jennifer or Sara at 952-746-5151 or info@lupusmn.org.

Here are a few ways to be a part of this event:

- 1. Golf.** Join us as an individual or bring a group of friends for the day.
- 2. Sponsor.** Corporate sponsorships are available at varied dollar amounts. Put your company's name on an aspect of the tournament such as the trivia contest or an exclusive hole.
- 3. Donate.** Consider making a cash or credit card donation that will go directly to lupus research.
- 4. Advertise.** Use either a course sign or a program advertisement to get your company or product in front of the day's golfers.
- 5. Volunteer.** We always have roles for volunteers on tourney day with registration, hole contests, mulligan sales, etc.
- 6. Give.** Consider donating a raffle prize or auction item.

No matter how you choose to get involved with the event, you'll be supporting the Lupus Foundation of Minnesota and our mission to fund research into the cause and cure of lupus.

Health Secretary's Report to Congress Validates Importance of Lupus Education

A major report on lupus from the Secretary of Health and Human Services to the U.S. Congress on January 22 reviews the state of lupus and documents the need for a comprehensive national provider health education program to help eliminate the barriers of racial disparities in the early medical diagnosis and treatment of lupus.

The new education program is led by the Office of Minority Health in the federal Department of Health and Human Services in partnership with the U.S. Surgeon General and the Office of Women's Health and implemented through the American College of Rheumatology (ACR).

The Secretary's report highlights the effect of disparities on lupus patients, stating that "many still die prematurely from lupus because of complications of the disease, late diagnosis and co-occurring chronic conditions."

It also documents the need for health education efforts, noting that "until researchers discover a cure or new ways of identifying at-risk individuals as well as diagnosing and treating lupus, educating health care professionals about the importance of early diagnosis and teaching patients how to manage and cope with lupus provides the best opportunity for improving quality of life for patients and for controlling morbidity and mortality."

These findings substantiate the work of the Lupus Foundation of Minnesota and the work of our Client Services. As our mission declares, education and support are important to improving the lives of those affected by lupus.

We continue to develop educational programs designed to address quality of life and management strategies for living with lupus while also reaching out to the professional community with programs intended to raise awareness of issues and offering tools and techniques in working with those diagnosed.

For a complete listing of services offered by the foundation, please contact a Client Services representative at 952-746-5151.

Excerpts from Lupus Research Institute News Release, January 22, 2010

LFM Client Services Partners with Pathways

On consecutive Tuesdays, beginning April 6, and running through May 11, Vice President of Client Services Cheryl Como will be offering the patient education class, "Creating Your New Normal," through Pathways Minneapolis.

In Creating Your New Normal, participants are encouraged to explore and cultivate possibilities for incorporating a chronic or life-threatening disease into their lives. Objectives are to provide tools, interaction, and challenges that offer a new direction in living and loving your life.

"This program aligns with Pathways' mission of helping one to look at what life has presented through illness and how to make the most of your life with tools which help show you the positive side of what you do have," say Pathways Executive Director Tim Thorpe. "It encourages engaging in your own self-healing by learning how to incorporate your illness into your lifestyle—as part of it, not as an obstacle."

Pathways is a non-profit, volunteer-sustained organization that provides programs and an environment designed to support a creative healing response for people with life-threatening illness and urgent health problems

The six-week program is free, but pre-registration is required. To learn more about Pathways or to register, visit www.pathwaysminneapolis.org or call 612-822-9061.

"Living with Lupus" LFM Featured on Local TV

Lupus and the Lupus Foundation of Minnesota were recently featured on "Set It Up," an after-school, teen-produced, magazine-style TV show on the Saint Paul Neighborhood Network (SPNN).

Produced by youth producers Ekemini Jonathan and David Hoh, the "Living with Lupus" segment features Ekemini herself, as a teen living with lupus, and LFM's Vice President of Client Services Cheryl Como. The feature was designed to raise awareness of lupus through her experience and through facts presented by LFM.

"It is our hope that media pieces produced by youth at SPNN will be used to engage the community and inspire change," said Mike Wassenaar, Executive Director of SPNN.

SPNN Youth Programs provides Saint Paul youth with the opportunity to create community media with a lasting impact while at the same time developing skills in media production, critical thinking and community awareness. Teens work both behind and in front of the camera as producers, crew and talent for the production.

"Set It Up" airs every Monday night at 7 p.m. on YTV-Channel 16 in St. Paul. The "Living with Lupus" segment can be viewed from a link on the LFM website on the "press" page.

Customized 5K Training with LFM

RunMantra offering LFM training group, chance to meet others and train for Lupus 5K.

As the Lupus Foundation of Minnesota is prepping for the Lupus Walk for Hope and 5K Trail Run, we're also offering you the opportunity to prep along with us!

Question: Have you wanted to run a 5K, but don't know how to get started?

LFM, with partner RunMantra, is offering a fully customized, six-week 5K training program that will culminate at the September 11 Twin Cities Lupus 5K Trail Run at French Regional Park in Plymouth. RunMantra and their certified coaches will craft an individually based training schedule for you based on your experience, goals and capacity that will fit into the six week training.

Beginning on August 3, there will be two weekly runs—on Tuesday in the early evening and Saturday mornings. The run will begin and end in the Bloomington and/or Plymouth areas and will be conducted on trail courses.

A classroom session following one of the weekday runs will offer you diet and nutrition awareness training. Participants will also have access to online coaching via RunMantra's website.

The cost will be \$75 per participant, supervisor by a certified trainer, a personalized program, a classroom session on diet and nutrition and entry into the Twin Cities Lupus Walk for Hope and 5K Trail Run on Saturday, September 11!

Don't miss this opportunity to start training for our 5K. The group is open to individuals of all skill levels and abilities. So whether you've never run before, just need to shake off the dust or want some peer support to motivate you, this is your chance. Grab your friends and get moving.

If you have questions or wish to register for this training program, please contact Sara at 952-746-5151 or email to sotto@lupusmn.org.



“Lupus Updates” is First in a Series of Educational Workshops



Dr. Ali Sajjad

Lupus Foundation of Minnesota’s Client Services will be hosting workshops on a range of topics throughout the year in a variety of locations.

The first on February 12, “Lupus Updates with Dr. Ali Sajjad,” was held at the Woodwinds Health Campus in Woodbury where 14 participants were led through an informative session about lupus, the immune system and treatments.

Throughout the hour-long presentation, Dr. Sajjad addressed a number of points and answered questions from those in attendance. Following is a recap of some key points of Dr. Sajjad’s talk:

“Prevention is the best tool in the face of no cure.” Dr. Sajjad spoke about the importance of the patient developing the habit of listening to what their body is telling them regarding an impending flare or other disease activity.

“There is no test for a flare, but body systems will talk.” Try to read your body; it can make the difference between going to the doctor and going to the hospital. He did indicate that there is one system that fails to give advanced warning, the kidneys.

A participant asked, “If someone is in a flare, who should they contact first, their primary doctor or their rheumatologist?” Though he himself is a rheumatologist, Dr. Sajjad advised to not underestimate the knowledge of your primary doctor, saying they too have a great deal of knowledge about the body and about you.

“Every meeting with a patient is about starting over again,” said Dr. Sajjad. When he meets with his lupus patients, he has a 15-20 minute time slot every three months. He recommended being prepared to both talk and listen at an appointment, stressing the importance of learning together as each patient experiences lupus differently.

“I learned about lupus in medical school, but in meeting with patients, I want to learn how their lupus affects them.” Dr. Sajjad said the learning continues as both doctor and patient work together in discovering the different affects of lupus on each individual.

Watch our website and Facebook for the May workshop, “Navigating Insurance and Disability.” Experts in disability law and insurance will address the disability application processes and highlight resources available to the un-insured.

“Hit for Lupus” Scores for Lupus Foundation of Minnesota

UWRF Falcons Host Softball Game for Lupus

The University of Wisconsin-River Falls Falcons will host the first annual “Hit for Lupus” softball game on Saturday, April 17. All donations will go to the Lupus Foundation of Minnesota.

The driving force for the game is Junior Dana Book, originally from Brooklyn Center. Dana and the team are inspired by her mother Lorri Book who has struggled with this disease for 37 years.

Dana says “This disease has affected my family as well as many others throughout the years. The softball team is a second family to me and has been there for me and we wanted to raise awareness and funds for LFM.”

The game will feature t-shirts for \$10, concessions, and a coupon for a free popcorn will be awarded to everyone who makes a donation on game day.

The opening pitch will be thrown at 3 p.m. by the inspiration of the game, Lorri Book.

The game will be held at River Falls Ramer softball field, right behind Hunt Arena on the campus. All are welcome to cheer on the Falcons as they “Hit for Lupus.”


Visit the Athletics page of the University of Wisconsin River Falls website, www.uwrf.edu for further information on the 2010 Falcon softball team.






2010 UWRF Falcons Softball Team including Junior and “Hit for Lupus” organizer Dana Book (front row, center).

Community Support Groups

Support groups have been shown to have a positive effect on the wellness of a lupus patient. It is a way to share personal stories, be introduced to educational materials and resources, and socialize with others who understand the challenges of living with lupus. The following is a list of groups that are being conducted.

This symbol  denotes groups that are conducted by a certified LFM Support Group Leader and occur in consultation and in collaboration with the Lupus Foundation of Minnesota.

TWIN CITIES AREA GROUPS			
City	Address	Date & Time	Contact(s)
Anoka/Ramsey 	Committee Room, Anoka City Hall 2015 First Avenue North Anoka, MN 55303	Last Wednesday 6:00 – 7:30 PM	Maria Buchholz 763-323-7155 paixao72@q.com
Bloomington	Christ the King Lutheran Church 8600 Fremont Avenue S. Bloomington, MN 55420	Third Monday 7:00 – 8:30 PM	Judy Johnson 952-831-4722 jjohnson6@ties.net Arlene Knutson 952-881-8558
Maple Grove 	Community Room at Byerly's 12880 Elm Creek Boulevard North Maple Grove, MN 55369	Third Thursday 6:30 – 8:00 PM	Wanda Gross 763-496-1138
Roseville 	North Como Presbyterian Church Memorial Lounge 965 Larpentour Avenue West Roseville, MN 55113	Third Thursday 7:00 – 8:30 PM	Steve Sarrazin 651-488-2066
St. Louis Park 	Community Room at Byerly's 3777 Park Center Boulevard St. Louis Park, MN 55416	Third Tuesday 7:00 – 8:30 PM	Deb Turner 763-585-0342 propturner@yahoo.com

OUTSIDE METRO AREA GROUPS			
City	Address	Date & Time	Contact(s)
Alexandria	Call for location.	Call for dates and times.	Karla Lysen 320-634-0276
Duluth 	Saint Mary's Hospital Oncology Classroom (4th Street Entrance) 407 East Third Street Duluth, MN 55805	Last Wednesday 7:00 PM *No summer meetings (July – October)	Jody Anderson 218-525-0677 jodette_99@yahoo.com
Mankato	Call for location.	Third Thursday 2:00 PM and 7:00 PM *No summer meetings	Nadene Sandon 507-345-8950 Diane Beyer 507-388-8991
Rochester 	Meadow Lake Senior Living Group 22 45th Avenue NW Rochester, MN 55901	First Saturday 10:00 AM *No summer meetings (June – August)	Carolyn Hyland 507-292-0945 curelupus@charter.net
St. Peter 	Country Kitchen 814 N. Minnesota Ave. St. Peter, MN 56082	Third Thursday 1:00 PM	Sue Schott 507-246-5247
Willmar	McMillan's Restaurant 2620 First Street Willmar, MN 56201	Last Thursday 2:00 PM	Janelle Joneson 320-796-5119

OUT OF STATE GROUPS			
City	Address	Date & Time	Contact(s)
Bismarck, ND	Elks Lodge 900 S. Washington St. Bismarck, ND 58504	Second Thursday 12:00 PM	Dave & Jan Jundt 701-258-6345
Rapid City, SD 	Black Hills Arthritis Association Office, Midtown Plaza 429 Kansas City St. Rapid City, SD 57701	Second Saturday 9:00 – 11:00 AM	Nickie Steinback Call before 8:30 PM please. 605-721-2864 lupus@rap.midco.net



Monthly Buddy Lunches

Second Wednesday of Each Month

(April 14, May 12, June 9, July 14)

11:30 AM – 1:30 PM

Lupus Foundation of Minnesota Office


The Atrium, 2626 E 82nd St., Bloomington, MN 55425

The purpose of the buddy lunch is to connect clients and supporters in a relaxed setting with discussion centering on lupus-related topics. This is an open-ended service. For more information or to RSVP, contact a member of Client Services at 952-746-5151 or 800-645-1131.

Telephone Support

Telephone Support Volunteers have a personal interest in and/or experience with lupus and are available for those times you need to talk.

VOLUNTEER TELEPHONE SUPPORT		
City	Contact(s)	Phone
Brainerd	Barb Worms Yvonne Hjelm	218-829-8535 218-829-3032
Dickinson, ND	Alena Praus	701-483-9454
Duluth	Jody Anderson	218-525-0677
Eau Claire, WI	Allison Claussen	715-723-4362
Faribault	Linda Pansier	507-334-2677
Hutchinson	Sheila Mogard	320-587-6829
Maple Grove	Sandi Olson	763-550-1663
Rochester	Carolyn Hyland Alicia Farmer	507-292-0945 605-670-2951
Sioux Falls, SD	Sioux Valley Healthformation Line	605-333-4444
St. Cloud	Karen David	320-393-4206
Twin Cities	Patty Krageland Patricia Walsh	651-699-2332 952-929-3547

SUPPORT IN SPANISH		
Twin Cities 	Gustavo Taberna, LFM	952-746-5151
Twin Cities	Sarys Gomez-Lira	651-735-0566

Please take note it is important that you consult a medical professional for any concerns regarding symptoms, medication or care. Support services are neither staffed nor supervised by medical professionals.

Thank You to Our Contributors DECEMBER 1, 2009 – FEBRUARY 28, 2010

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Kris Mondeel-White
Don and Karen Wolf
Steven and Karen Ytterberg

Continued on page 11...

Support the Lupus Foundation of Minnesota

If you wish to support the Lupus Foundation of Minnesota, use this form to indicate your donation.

My gift is enclosed for: \$25 \$50 \$75 \$100 \$250 \$500 Other _____

I have enclosed a check for the amount noted above.

I'm authorizing my gift be charged to my credit card. Visa MasterCard

Card No. _____ Expiration Date _____

Signature _____ Email address _____

Name (please print) _____ Phone _____

Address _____ City/State/Zip _____

Contributions are tax deductible as provided by law. Please enclose this form with completed credit card information or your check in an envelope and mail to us at: **Lupus Foundation of Minnesota, 2626 East 82nd Street, Suite 135, Bloomington, MN 55425-1380.**

Thank You to Our Contributors

DECEMBER 1, 2009 – FEBRUARY 28, 2010

Continued from page 10...

Community Funds:

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Community Health Charities MN

Ladies Auxiliary to Hibbing,
Fraternal Order of Eagles, Aerie #4456

Microsoft Matching Gifts Program
on behalf of Nancy Petersen

United Way of Central and Northeastern
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on behalf of Ronda J. Bandy

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Tina Ameter Peterson

Gloria and Craige Farwick

The St. Peter Area Lupus Support Group

Lee and Sue Schott

Sheri Robinson

Joseph and Joan Janzen

Terri Walker

Travelers Foundation on
behalf of Kelley J. Meyer

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To Schedule Pickup Service

Call **651-748-0400** or go online to www.lupuspickup.org

Your generous contributions will enhance the service mission of the LFM!

STORE LOCATIONS that accept contribution items designated for LFM:

- 1) Unique Thrift Store
1657 Rice Street
Roseville
651-489-5083
- 2) Unique Thrift Store
2201 37th Ave NE
Columbia Heights
763-788-5250
- 3) Unique Thrift Store
4471 Winnetka Ave N
New Hope
763-535-0200
- 4) Unique Thrift Store
14308 Burnhaven Drive
Burnsville
952-898-0988
- 5) Valu Thrift
2145 Hudson Road
St. Paul
651-702-5920

Thank you to all of our faithful contributors who use the pickup service to make donations to the Lupus Foundation of Minnesota!

As a helpful reminder, we aren't able to take your computer monitors or TVs bigger than 25" or those having turn style knobs, and no console TVs, please. Again, we're grateful for your generous donations!

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UPCOMING EVENTS

Monthly Buddy Lunches

Second Wednesday of Each Month (April 14, May 12, June 9, July 14)
11:30 AM – 1:30 PM

Lupus Foundation of Minnesota Office (Third Floor Conference Room)
The Atrium, 2626 E 82nd St., Bloomington, MN 55425

The purpose of the buddy lunch is to connect clients and supporters in a relaxed setting with discussion centering on lupus-related topics. This is an open-ended service. For more information or to RSVP, contact a member of the Client Services Team at 952-746-5151 or 800-645-1131.

Monthly Support Group Meetings

13 monthly meetings offered throughout Minnesota, North Dakota and South Dakota
Refer to Page 9 for the complete listing and further details.

Cory (a.k.a. Sludge) Cove's 24-Hour On-Air Marathon for LFM

Saturday and Sunday, April 17-18

2 p.m. – 2 p.m.

Tune in to 1130 AM or listen online at www.kfan.com (the best option for Greater Minnesota or worldwide)

Get as much Sludge as you (or your radio) can handle as KFAN presents 24 hours of Sludge/Cory Cove. Starting at **2 p.m. Saturday until 2 p.m. Sunday**, Cory will be talking nonstop—about sports, lupus and other random things—auctioning sports memorabilia hourly and taking donations, all to raise money and awareness for the Lupus Foundation of Minnesota. Call in. Donate. Bid.

SAVE THESE DATES

2009 Lupus Foundation of Minnesota Annual Meeting and Fundraiser

Tuesday, May 18, 2010

For more details see page 3 or call the Lupus Foundation of Minnesota at 952-746-5151 or 800-645-1131 or info@lupusmn.org.

2010 Lupus Golf Classic

Wednesday, July 7, 2010

Noon Shotgun Start

StoneRidge Golf Club, Stillwater, MN

Sponsorships available now. Contact Sara Otto at 952-746-5151 or email sotto@lupusmn.org.



Lupus Walk for Hope

Twin Cities – Saturday, September 11

Rochester – Saturday, September 18

More information forthcoming.

Sponsorships available now. Contact Sara Otto at 952-746-5151 or email sotto@lupusmn.org.



LUPUS NEWS

The William Flies family dedicates this issue of 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.

Lupus News is published quarterly by the Lupus Foundation of Minnesota. Please keep us informed of address changes. The Lupus Foundation's phone numbers are **952-746-5151** and **800-645-1131**. Our web address is www.lupusmn.org.

If you're interested in receiving an electronic copy of this newsletter, please send a request via email to info@lupusmn.org.