



Lupus News

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“Pay It Forward” By Nancy Palmer

Nancy Palmer is a very involved member of the Lupus Foundation of MN. She has a BA in art education and a masters in occupational therapy. Nancy worked as an occupational therapist prior to retiring due to complications related to her lupus. She has recently started to paint in watercolors and enjoys spending time spoiling her grandniece and other children in her life.

Turning forty brought many changes to my life. A name was put to the symptoms that I had felt since at least junior high. I had surgery to release a tight hip muscle fascia (ITB) and three days later I was hospitalized with polyarthritis and a rash on my hands. When all the labs were back my doctor felt that I had rheumatoid arthritis; I sought a second opinion. After two days of testing, I was given the diagnosis of systemic lupus erythematosus (SLE). My car had SLE on the side near the windows. Wow, I'm a special limited edition too! The lupus also affected my muscles and kidneys. In 1974 I was very ill, but no one could figure out why (including the clinic who would diagnose me eighteen years later). The rheumatologist stated that I could make a good case for lupus at that time. Every test except DNA was run; as many know, lupus is not an easy disease to diagnose.

For my lupus treatment I was put back on prednisone and plaquenil for the rash, told to go home and read,

weigh myself and take my blood pressure daily and stay out of the sun. I was working as an occupational therapist, but my knowledge of lupus was limited. Most of the people that I know had poor outcomes. Taking a nap daily was common for my friend's mother who had lupus; I would learn why they were necessary.

Fear overcame me. Would I live to my next birthday? How could I do my job that involved hand strength and dexterity when my hands hurt just clipping out the coupons in the Sunday paper? How would I find energy to work when all I wanted to do was to lay my head on the desk by 9:00 A.M.? I usually started work at 8:30 A.M. We took a coffee break when we first came. A co-worker of mine had lupus and gave me the book by Henrietta Aladjem called *The Sun is My Enemy*, as well as some Lupus Newsletters. I contacted the Foundation's office for a complete list.

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“Lupus doesn't need to ruin your whole life. You are a person with knowledge, skills and interests. It is a learning experience in how you can adapt them to your new lifestyle.” — Nancy Palmer





“Pay It Forward” *Continued from front page...*

By Nancy Palmer

Education was alleviating some fears, but that wasn't enough. I contacted the West St. Paul (now Inver Grove Heights) support group leader for myself and Rochester's leader for mom and me in order to help her with her fears. Support groups were not new to me. My occupation therapy background included at least a semester of group processes plus a psychiatric internship. I organized a support group for stroke victims and their families in Wisconsin and took one over in Minnesota. I was a frequent speaker at other support groups, and ironically had been asked to speak at a lupus support group in Wisconsin, but moved to Minnesota instead. Would history have changed had I stayed in the area?

I became a regular at the West St. Paul support group that I now co-facilitate with Mary Joyce. I learned that people could live real/regular lives, but priorities would have to be different. I didn't have to explain myself to the group. A schedule conflict would have me looking for another group for support. I ended up at Park Nicollet where I was a member and a co-facilitator with Joyce Johnson. I stepped down from the leadership role when I became a caregiver in my family. I still try to make the Christmas and summer potlucks on Joyce's porch

How else have I learned to cope with this strange and sometimes mysterious disease? The rheumatologist told me to wear long sleeves, pants, a four-inch brimmed hat and sunscreen (even when it's cloudy) and sunglasses to protect my eyes. As a lake person all of my life that all seemed to be restrictive. I purchased two sun shirts (check with the Foundation for suggested resources). I decided then to collect large brimmed hats so that I could match all my outfits and have ones that would travel well. Remember too that some medications make you more sensitive to the sun in addition to the lupus. Also, stay well hydrated. I am an advocate for water. It is calorie free and keeps the body working better. Avoid carbonated beverages, especially colas as they decrease your bone density.

About a year after my lupus diagnosis I was diagnosed with Sjogren's syndrome, another autoimmune disease that affects the moisture producing exocrine glands in the body. I was told to use eye drops four times a day, but the doctor didn't tell me that it was also a systemic disease like lupus. The Twin Cities Sjogren's Group was having a meeting not long after my diagnosis. Dr. Nelson Rhodas was one of the many speakers. He is an oral pathologist at the University of Minnesota Dental School. Sjogren's syndrome is his area of research. About six years ago he twisted my arm to be a patient educator for the "Newbies" (first year dental students). I would be their first live patient. They take a history and do an oral exam. I recruited Mary Joyce, my co-facilitator. We have streamlined our medication lists and histories. Our job is to get them to ask the right questions, look for any anomalies and pathologies in our mouths and start to synthesize information while they learn to chart. Each group of 4-6 students has their own strengths. Dr. Rhodas either supervises or stops down to check in. I get to count it as an exam for him and he renews my meds. If you counted all the oral exams that I've had in the past 6 years, I'm probably good for another 25. We get plenty of "warm fuzzies" from the students by helping to educate them and ensuring that the more people exposed to Sjogren's, lupus and other autoimmune diseases the more everyone will benefit.

Taking an active role in any organization makes you own it and belong. I'm not a pew warmer, even though there are times that the lupus has been active or family obligations have made me pull back to keep me from a major flare. Stress has been a significant factor in my lupus activity and my friends would attest that my life has been a big soap opera. Presently, I am doing quite well except for when I do more than my body is ready for. I'm fighting back from a state of reconditioning and 16 years of prednisone; need I say more? The Lupus Foundation has given me the opportunity to volunteer in positions from mailings, speaking at support group trainings, phone calls, Baker's conventions, doing programs at support groups, wine and beer taste testing fundraisers, ASID sales, garage sales and a nearly perfect record of walk attendance. These are only some of the things I have done, which are among the many opportunities out there that can help you leave the security of your house or the downward spiral of depression. The foundation is adaptable. They can put you in a position suited to your abilities and interests. I find when I give to others I feel better and meet new friends. Without lupus and Sjogren's I would not have had the rich life I have experienced. Not that I wouldn't have given away the pain and fatigue, but my friends have helped me cope with the bad times

and rejoice in the good ones. Lupus doesn't need to ruin your whole life. You are a person with knowledge, skills and interests. It is a learning experience in how you can adapt them to your new lifestyle.

So fight your fears with faith, support and education, but "pay it forward." Get out and volunteer and let humor rule your life. Hats off to you all! But remember to use them in the sunshine!

Lupus Golf Classic SET FOR JULY 11, 2007

There's still time to reserve a spot at the
9th Annual Lupus Golf Classic
taking place at StoneRidge Golf Club
on Wednesday, July 11!

A few foursomes remain to be filled so if you'd like to participate in any way, just **contact Bill Jenison at (952) 746-5151 or bjenison@lupusmn.org**

A PDF file of the event brochure is on the Foundation website, www.lupusmn.org

Enjoy a great day of golf and fellowship while making an important contribution to fund lupus research!





The Diet Disconnect...

Reconnect with reality to improve your health By Lina Wade

Most Americans are well aware of the importance to eat healthy. Unfortunately, bad choices and misconceptions often get in the way. For example, 56% of Americans surveyed by the International Food Information Council (IFIC) Foundation said they were currently trying to lose weight. Nine out of ten, however, were unsure how many calories to eat each day (*and almost half wouldn't even wager on a guess*).

The IFIC Foundation surveyed 1,000 adults over a three-week period during February and March for its second annual Food & Health Survey. Participants were questioned about attitudes toward food, health and nutrition. Six major “disconnects” – conflicts between our perceptions on diet and health and what we actually **do** – were revealed here, according to IFIC Foundation President Susan Borra, RD. She says “These diet disparities highlight the gap between our desire to be healthier and the reality of how to make changes in day-to-day behavior.”

THE 6 DIET DISCONNECTS

Here are the major areas where discrepancies were found between our perception and reality – this can deter us from adhering to a healthier diet and lifestyle.

Breakfast

According to 90% of Americans and most dietitians, breakfast is the most important meal of the day; still, less than half (49%) actually eat it each morning. If this sounds like you, dietitians recommend stocking your kitchen with healthy “grab and go” breakfasts such as whole-grain cereal or cereal bars, low-fat yogurt, and hard-boiled eggs.

Calories

More than 2/3 of those who reported trying to eat healthier said they were doing so in an attempt to lose weight. Yet only 11% of Americans knew how many calories they should consume daily. To find out your own recommended calorie level, visit <http://www.mayoclinic.com/health/calorie-calculator/NU00598>

OR <http://mypyramid.gov/>

Carbohydrates

We are getting the message that some types of carbs can improve the diet. Over 70% of those surveyed said they are trying to eat more fiber and whole grains. Although the low-carb diets have recently decreased in popularity, more than 50% of Americans are still uncertain about the amount of carbohydrates to consume.

Diet and Exercise

Most Americans (84%) claim they are physically active at least once a week – but 44% of them say that they don't balance diet and activities to manage weight. Bonnie Taub-Dix, RD, a spokeswoman for the American Dietetic Association, says “Consumers need to understand that calories have to be balanced with physical activity – either by eating less or exercising more to achieve weight control.”

Fats

Concern about how much and what type of fats we eat is up from a year ago (from 66% to 72%) and the spotlight is now on consuming less **trans** fats. But it seems we're as confused as ever about which fats are actually healthier. Some survey participants said they were trying to eat less polyunsaturated fats, but this is one of the fats recommended for health benefits. Healthier fats are canola, olive, corn and safflower – though it's important to keep in mind that all fats are high in calories.

“Functional” Foods

According to the survey, Americans believe that consuming specific foods or beverages can provide health benefits, like improving heart health (80%); digestive function (76%); and energy or stamina (76%). Yet more than 50% of those surveyed say they don't actually consume food or beverages that deliver these benefits.

Eating Healthier – All Foods CAN Fit Into a Healthy Diet!

Despite these disconnects, some positive health messages are getting through. For example, the survey found that Americans are getting the message that all foods can fit into a healthy diet. “We saw a shift away from people being reductionists, or consuming less food and beverage, to eating more healthful food and beverages,” says Borra. Taub-Dix adds, “Balance is essential. You can't just focus on calories or fats. You need to turn over packages and look at the nutrition label to choose foods that are rich in nutrients and reasonable in calories.”

Dietitians strongly suggest that rather than trying to find the perfect diet or exercise routine, we should aim to make smaller, more gradual improvements in diet and exercise behaviors.

If Americans did nothing more than cut down on portion sizes and add a bit more activity, it could make a big difference. Make a list of the things that you could improve and each week tackle one of the behaviors; focus on changes that are small, doable and sustainable within the demands of a busy life.

Dietary choices play an important role in reducing the risk for many chronic conditions. For everyone, there is always room for improvement – so assess your current eating habits to see what you can do to live healthier!

SOURCES
 News release, International Food Information Council Foundation.
 U.S. Department of Agriculture web site, mypyramid.gov.
 Susan Borra, RD, president, IFIC Foundation.
 Bonnie Taub-Dix, RD, American Dietetic Association spokeswoman

LFM's Student Summer Research Fellowship Program Going Strong at 27 Years

As far back as 1981 the Lupus Foundation, then staffed by dedicated volunteers, was invested in developing the scientists of the future. Members raised funds to support college students spending their summers in the laboratory at the University of MN learning about lupus while assisting the physicians and scientists. This program provides students who have strong interests in science, medicine and research with an opportunity to have first hand exposure to the nature of medical research.

The founders of this program were insightful and deserve much credit for having fostered a program that has supported eighty-five fellowships over those twenty-seven years; more than \$300,000 has been invested by the Lupus Foundation of MN for the development of these future scientists and physicians! This summer four students at the University of MN and two students at Mayo Clinic will have fellowships under the direction of inspired clinicians who are deeply committed to their lupus research. **We are all grateful for the many people who have had a role in shaping this program over the years.**

Camp SUNSHINE

A RETREAT FOR CHILDREN WITH LIFE-THREATENING ILLNESSES AND THEIR FAMILIES

Camp Sunshine supports children with life threatening illnesses and their families. The camp has the distinction of being the only program in the nation whose mission is to address the impact of a life threatening illness on every member of the immediate family—the ill child, the parents, and the siblings. Since its inception, Camp Sunshine has provided a haven for over 16,000 individuals from diverse cultural backgrounds.

Families with a child diagnosed with diseases such as lupus and other life threatening illnesses attend one of the week-long camps. The focus of Camp Sunshine is on alleviating the strain that lupus takes not only on the sick child but also on other family members. Families have an opportunity to rebuild their relationships together and meet other families facing similar challenges.

Free quality services are provided at the camp including accommodations and meals, onsite medical services, counseling services, and recreational facilities. While the camp is in session, each family stays in their own family suite. Breakfast, lunch, and dinner are served each day.

Volunteers, except for those who live nearby, also stay on the property. Camp Sunshine is staffed almost entirely by volunteers, many of whom return year after year. The volunteers reflect the diversity of the families and help with recreational leadership, childcare, food service and whatever else needs to be done.

Another distinctive component of the program is the medical facilities and professional staff that are available to address the taxing physical needs of children with

intrusive diseases. A physician is located at the camp for the entire session so that families can be secure in the knowledge that the camp offers 24-hour onsite medical support. In addition, a hospital with full-time emergency room physicians and pediatricians is only 25 minutes from the camp.

Thanks to the generous support of Jenna's Fund, the Lupus Foundation plans to sponsor two families for a week long stay at the twenty-three acre lakeside campus this summer. For more information please contact Timberly Williams at (952) 746-5151 ext. 104 or visit our website www.lupusmn.org

Unlocking the Mysteries of Lupus for Native Women

By Sheryl Scott, MPH

"Lupus coming into my life brought about a major shift in my lifestyle," says Maria McCoy, a Turtle Mountain Ojibwe woman living with lupus for over a decade. "I had to take a hard look at myself and found that I was out of balance. I was in an unhealthy relationship, living under a lot of stress and not doing the basic things every person should do to live a healthy lifestyle. The changes I have made brought transformation for me in so many ways. I now am living well with lupus."

Northern Tribes Suffer High Rates of Lupus

Maria's is one of many untold stories of Native American women who are living with lupus. Unfortunately, very little research has been conducted on how many Native women suffer from this condition, and little attention has been paid to how lupus impacts this community. But because of a recent project funded by federal Office of Women's Health, the Twin Cities community has had the opportunity to learn more. "When we looked at the few scientific articles that had been published, we were alarmed at the disparities suffered by Native people in the United States and Canada," reports Sheryl Scott, MPH, and project coordinator. "Especially that tribes in our area show rates 3 to 15 times higher than expected, along with poorer outcomes. Distressingly, Native children are at higher risk. We knew we needed to do something to reach community members with important information on this disease."

Drawing On Cultural Strengths

American Indian tribes have unique cultural backgrounds which need to be addressed when developing health education, prevention and treatment. A good example is in the very name of the disease: Lupus is the Latin name for wolf, an animal feared and even considered evil in European cultures. In stark contrast, many tribes hold the wolf in high esteem, recognizing its power and admiring its ability to survive in the natural world. The wolf is a central figure in teaching stories and lessons for many tribes.

Keeping such issues in mind, a team of community members, including Ms. Scott and Andrea Law of Scott Consulting, Jennifer Irving and Maria McCoy of the American Indian Family Center, and Gustavo Taberna of the Lupus Foundation of Minnesota, worked throughout the spring of 2007 to plan and implement four educational sessions that would take into account the culture of Native women. The team used the successful OWH "Unlocking the Mysteries of Lupus" model, which fits well with Native culture given its emphasis on a holistic approach. Many tribal communities draw on a holistic circle or "Medicine Wheel" encompassing spiritual, social, mental and emotional components of being. Addressing these areas, the sessions included a Native psychologist (Dr. Jessica Gorneau of the American Indian Family Center), a disability attorney with 30 years of experience (Martha Eaves, Southern Minnesota Regional Legal Services), a Native woman living with lupus (Maria McCoy, American Indian Family Center) an educator on traditional Native healing (Cheryl Secola, Indian Health Board and Division of Indian Work), and a speaker on social services available to people living with lupus (Gustavo Taberna, Lupus Foundation of Minnesota).

Participants heard about the medical aspects of lupus from area rheumatologists (Dr. John Schousboe, Dr. Barb Segal and Dr. Ali Sajjad), the wonderful array of social services available from staff of the Lupus Foundation of Minnesota, and practical tips on how to navigate the confusing paper maze to receive disability from attorney Martha Eaves (which one participant dubbed "nuggets of gold"). Three Native women from the Twin Cities served as cultural anchors for the sessions. Maria McCoy led the group in an opening with a sage purification, then shared her personal story and invited the group to share their question. Psychologist Dr. Gorneau, (Turtle Mountain) outlined the terrible price of historical trauma among Indian people, but yet used humor (an Indian strength!) and personal stories to remind participants about their positive assets and ways of coping that have helped Indian people survive, and even thrive. Cheryl Secola (Bois Forte Ojibwe) ended the session by speaking from the heart about the importance and strength of connecting with tribal traditions, and drawing on the knowledge of elders.

Next Steps

"Many people are misinformed about American Indians and health care," emphasizes Sheryl Scott. "They just think 'oh, the government takes care of them, or the casino pays for it'. Well the truth is far different. The Indian Health Service, the government body responsible for health care for American Indians, is woefully under-funded and very often provides no access to specialists. During the mid-1900s, the U.S. government tried to assimilate Indian people by moving them to urban areas, and those individuals now have to struggle for access to health care as they are away from their reservation or are not officially enrolled." The good news is that some tribes are gaining ground economically, and for people enrolled in those tribes, health services are getting better. The challenge is to reach those who are unaware and continue to suffer without access to health care or the social services provided specifically for people with lupus by places such as the Lupus Foundation.

Gustavo Taberna, outreach specialist for the Lupus Foundation, is committed to continue this work with Native communities. In mid-July, the team will share an exhibit at the Living Strong conference sponsored by the Mdewakanton Sioux (Dakota). The free conference is one of the largest health events specifically for Native people in the region; 700 people participated in 2006. The community team has been invited to speak by conference organizers, and Maria McCoy will do the honors.

"We are here to help and be of service to others," Maria remarks. "But in order to live in balance we must take good care of ourselves as women and Indian people, and this is a gift not only to ourselves but to our community. I have learned this lesson in my experience living with lupus."

* Note: The terms American Indian, Native American and Native are all commonly used terms for this community.



Lupus Walk for Hope



LUPUS FOUNDATION OF MINNESOTA

2007

"It's all about Research!"

TOGETHER We Will Find a CURE!

Join the Lupus Foundation of Minnesota as we Walk for Hope in Minneapolis and Rochester to raise funds for lupus research!

Plan to join walkers from all backgrounds for our 10th anniversary fundraising event!

The **Walk for Hope** raises funds to find better treatments and a cure for this debilitating autoimmune illness. We estimate there are *20,000 or more Minnesotans with lupus* who could benefit from the Foundation's outreach programs.

Mark your calendar! To make a difference and experience the team spirit with your family, friends, co-workers and others!

Raise Money! Find sponsors for the Walk by completing the Walk for Hope pledge sheet inside the Walk brochures. Contributions fund the Lupus Foundation's efforts to find a cure for lupus. Have your family and friends form a team! Encourage your team to raise at least \$250 for lupus research.

Walk! Have a great time at the Walk with your team and enjoy a day filled with entertainment, fun and food for walkers of all ages. Everyone participating will receive a T-shirt to wear with pride the day of the Walk along with hundreds of others in an effort to raise funds to help find a cure for lupus!

This year you can also participate in the Walk online through the **Virtual Walk**. Visit www.lupusmn.org for more details.

CHELSEA WEST

TO BE THIS YEAR'S WALK AMBASSADOR

Chelsea West has been selected as this year's Walk Ambassador. Chelsea is a senior at Anoka High School and has had a very successful high school career. Along with academics, her co-curriculars include: Concert Choir, theater, Star Club and the National Honor Society.



Outside of her school life, Chelsea has been an inspiration to many with her involvement in our Walks. Despite her young age, busy schedule and lupus diagnosis, Chelsea manages

to win the prize for having the most walkers on her team and raising a great deal of pledges for funding lupus research.

When asked what motivates her to walk, Chelsea says, **"I walk because I want to raise awareness and hope for a cure."**

Lupus Walk for Hope 2007 LOCATIONS

Minneapolis

Saturday, September 8, 2007

Minnehaha Park

Registration: 9:00-10:30 a.m. in the Minnehaha Park Pavilion

The **2-mile Walk** begins at 10:30 a.m. through beautiful Minnehaha Park

Rochester

Saturday, September 15, 2007

Silver Lake Park

Registration: 9:30 in the West Pavilion at Silver Lake Park

The **2-mile Walk** begins at 10:30 a.m. through the fall leaves of Silver Lake Park



WE SALUTE OUR TITLE SPONSOR!

How to Beat the Summer HEAT!

By Lina Wade

It's simple, really – “Slip! Slop! Slap!” as they say in Australia. Slip on a shirt, slop on the sunscreen and slap on a hat! The extent to which our skin can handle the sun, and therefore how much protection we need, depends on genetic factors. Red-headed, fair skinned people will require greater protection from the sun, whereas people with darker skin have more natural protection from the sun's rays. People with lupus are often affected by the sun, so one should take extra precautions when going outdoors – but everyone should protect themselves from the sun, as different skin types react differently to sunlight.

WHAT TO LOOK FOR IN A SUNSCREEN

Choosing which sunscreen to use can be difficult with all the choices available today. The most critical factors to look for when choosing your sunscreen are:

- Protection against both UVA and UVB radiation from the sun, often labeled “**broad spectrum**”
- Using the correct sun protection factor (SPF) for your skin type – a minimum of SPF 15 recommended

Sunscreen can last 2-3 years if it's been properly stored somewhere reasonably cool. Older products should not be used because they offer less effective protection.

SPF

Sun Protection Factor (SPF) measures how long a product protects against skin reddening from UVB rays versus how long it takes to redden *without* protection. For example, if it takes 10 minutes for your skin to burn without protection, applying sunscreen with an SPF of 15 will theoretically protect you from burning for 15 x 10 minutes.

GOLDEN RULES FOR SUN PROTECTION

- Always wear a sunscreen with an SPF of 15 or higher and apply to any uncovered area of the body. Clothing should be made from tightly woven fabric. It's a good idea to apply sunscreen everywhere if wearing light fabrics such as cotton.
- Sunscreen should be applied 30 minutes before being exposed to the sun, reapplied regularly and always after swimming.

- Wear a wide brimmed hat that will protect the back of your neck and ears and a loose fitting long-sleeved top.
- Remember that UV radiation is at its highest in the middle of the day, from 11am to 3pm, so try to avoid the sun during these hours or stay in the shade.
- Wear wraparound sunglasses or goggles that meet recommended standards which block 95% of UV radiation that can damage eyes and cause cataracts. For safety reasons, sunglasses for children should have plastic instead of glass lenses.
- It's especially important to keep children under the age of 3 protected from sun exposure at all times.

The good news is that by following these guidelines, you'll receive double protection: your skin will stay younger and smoother, and the risk of developing skin cancer and other complications is greatly reduced. But if you still spend some time soaking up the rays, make sure you take extra care of your skin after being in the sun.

Take cool showers or baths and apply lotion with aloe vera, calendula oil or cucumber extracts. For an extra cooling effect, try placing these items in the fridge. Make sure to drink plenty of water, the most comprehensive skin remedy around. Water is essential for digestion and absorption of vitamins, cleanses the body and is the necessary ingredient to keep skin cells healthy and looking good. There's nothing like water to keep both the skin and body hydrated and as cool as possible during the summer months.

So get out your sun block and hat! Make sure to have lots of water on hand, keep aloe or other skin treatments around in case of rash, bites, cuts or sunburn and safely enjoy the summer.



The X Chromosome's Role in the Genetics of Lupus

By John Haffner



The approximate 9:1 ratio of women with lupus compared to men with lupus shows that women are more prone to develop the disease. Dr. Qianjin Lu, of the Central South University in Changsha, China, along with Dr. Bruce Richardson and his team of researchers at the University of Michigan, conducted a study showing a connection between lupus and the X chromosome.

The human genome, with rare exceptions, is made up of 23 pairs of chromosomes (long strands of DNA that contain many genes). Within each pair, one chromosome is inherited from the father and the other from the mother. The chromosomes inherited from the mother and the father that make up these pairs are nearly identical. However, this is not true for the pair of chromosomes that determines the sex of the person. In this pair, the mother always contributes the X chromosome, but the father can either give an X chromosome of similar length, or a much smaller Y chromosome. A combination of two X chromosomes from the mother and father determines the sex of the person to be female, and if a Y chromosome is inherited from the father, the sex will be male.

Because the X chromosome is larger and contains more active genes than the Y chromosome, a process called **methylation** occurs in the X chromosome in order to ensure that the cellular functions of men and woman remain the same.

Methylation causes those unnecessary active genes in the X chromosome to become inactive. However, the opposite of methylation, **demethylation**, can cause those inactive genes to become active again. Lupus activity has been thought to have a connection with the demethylation of certain genes; Dr. Lu and Dr Richardson examined this connection to determine the greater prevalence of lupus in women.

A molecule called CD-40 ligand can sometimes be overproduced by the immune cells of women with lupus. The production of CD-40 ligand is directed by a gene that is located on the X chromosome, which can become activated through demethylation. The Lu-Richardson study showed that greater demethylation of the X chromosome resulted in greater expression of the CD-40 producing gene as well as greater disease activity. The researchers then concluded that this, in turn, may be a factor that helps explain why there is more lupus in women

Still, because lupus does not target women specifically, the role of demethylation within the X chromosome cannot explain entirely what the cause of lupus is. Although, any explanation that helps reveal the many mysteries of lupus and its complex origins brings us ever closer to a cure.

(Women and Lupus: The Inactive X Awakens, Qianjin Lu¹, Laura Tesmer², Ailing Wu², Donna Ray², Bruce Richardson². ¹Second Xiangya Hospital of Central South University, Changsha, China; ²University of Michigan, Ann Arbor, MI)

New Talents Promise to Make the Foundation Even Stronger

During the past year the Foundation has brought further awareness of lupus to many through education, fundraising and support. With 30 years of experience under our belt, we still plan to continue this tradition of growth and outreach. We are now excited to introduce some new, very talented people who will contribute greatly to the mission of the Lupus Foundation of Minnesota. With varying backgrounds and specialties, the two new staff members, summer intern and a visiting social worker joining us, will all be a welcome addition to the work we are doing here at the Foundation.

CYNTHIA ARNOLD

Cynthia Arnold has been named Vice President of Development for the Lupus Foundation of Minnesota. Cindy has a public relations and fundraising career spanning more than 25 years in nonprofits and major corporations throughout Pennsylvania, New York, Ohio and California.

“Every day, I am inspired by the clients I meet,” she adds. “Their stories of strength, spirituality and faith remind me of the important role we can all play in raising funds for research, education and outreach to help clients take charge of their lives and live better!”



Most recently, Cindy was the co-founder and President of Professional Media Consultants, a leading PR agency in State College, PA. The agency specialized in social issues campaigns such as a program to reduce infant mortality rates, and a project that reduced the stigma for people with disabilities by using the media. Her major clients included Penn State University, AccuWeather, Erie

County Drug & Alcohol Coalition and the Pennsylvania Developmental Disabilities Council. She has published articles in

Family Circle, Town & Country, Cosmopolitan and *1001 Home Decorating Ideas* magazines as well as the *Washington Post*, the *Centre Daily Times*, the *Erie Times News* and the *State College Magazine*.

She graduated from Ohio University with a B.S. degree in journalism and specialization in public relations. Currently, she is working on her Masters in e-business at the University of Maryland.

“Every day, I am inspired by the clients I meet.”

— Cynthia Arnold

SUZANNE BIDWELL

The Lupus Foundation of Minnesota welcomes Suzanne Bidwell to their staff. After years of living and going to school in Kansas, Suzanne is ready and eager to begin a new chapter of her career at the Foundation.

As the new Director of Client Programs, Suzanne says she was drawn to the Lupus Foundation because of her past experience working with people with chronic illness. Before starting her professional career, Suzanne received her Bachelor of Social Work and Masters of Social Work at the University of Kansas. Now, after years of working in the social work field, she is ready for a new location and a new challenge.

As a source for hope, strength, empowerment and comfort, clients of the Lupus Foundation of Minnesota will benefit thanks to Suzanne’s background and expertise. With experience in group work, she looks forward to bringing new



“The Minnesota social services system is on the leading edge.”

— Suzanne Bidwell

ideas to the support groups as well as incorporating new tools for success for clients as they take charge of their lives and live better!

There are some challenges to be faced when uprooting and moving to a new state, but the most positive aspect of her transition to the Lupus Foundation is the willingness of the staff to helping her acclimate to the new city.

Additionally, “The Minnesota social services system is on the leading edge,” says Suzanne, adding, “Building an effective network among these service providers will be a challenge I will truly enjoy.”

Suzanne previously worked within the KVC Behavioral Health Care and The Ryan White Program in social services. She says her greatest accomplishment has been her ability to maintain a fresh perspective for helping clients while maintaining a strong ethical code of conduct in respect to clients’ privacy and rights. The Lupus Foundation of Minnesota is proud to accept Suzanne Bidwell into their family and is excited about the many positive outlooks and changes she will be bringing with her.



ERIKA GALLAGHER

Erika Gallagher is the new Public Relations Intern for the Lupus Foundation of Minnesota. She will be a senior at the University of St. Thomas and will graduate next spring with degrees in Public Relations, Communications and Broadcast Journalism.

Erika has also done volunteer work for non-profits such as The Chloe T. Foundation, Families Moving Forward and Catholic Charities. “I hope to simply learn as much as I can and help as much as I can in the time that I am here,” explains Erika.

After Graduation, she hopes to obtain a position in non-profits and continue her work and serve a purpose.

HELI KANTOLA

Staff of the Lupus Foundation is eagerly awaiting the arrival of Heli Kantola from Jyväskylä, Finland in September. In March of this year, the Foundation was introduced to Heli through an email from Devjani Janhunen, a staff member of the University of Kuopio where Heli is working on her doctorate degree. It seems that our website (www.lupusmn.org) was the source of Heli and Devjani learning about the Foundation’s work in client services and triggered Heli’s interest to learn first hand about the role of a social worker in the United States. Heli’s training is in the field of social work and her research and doctoral dissertation will focus on the role of the social worker in caring for individuals with chronic illness, especially SLE.



Heli plans to stay in the U.S. for about three months, spending most of that time working at the Foundation. While she is here with us she will be supported by the University of Kuopio. We are very pleased for the opportunity to host Heli and further the Foundation’s mission through this cultural exchange. It’s also exciting to learn of the reach of our website. Expect to hear more about Heli’s visit in future issues of the newsletter.

I wish to *support* the Lupus Foundation of Minnesota

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Contributions are tax deductible as provided by law. Please enclose this form with completed credit 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.

A Short Course on Claiming Disability Benefits

By Michael G. Wagner

Social Security Disability Insurance (SSDI) benefits are available to workers who have “medically determinable” impairments that prevent them from staying on the job – or from performing any “substantial gainful activity”. SSDI is the safety net for workers who cannot be helped by adjustments and adaptations called “reasonable accommodations” in the Americans with Disabilities Act (ADA).

To be entitled to the benefits, a person must have worked at least five of the ten years immediately before the disability and paid FICA taxes. (*Exceptions and the way work time is counted are explained in the application instructions.*) The disability or impairments must be expected to last for at least 12 months.

How to begin

A claim for SSDI benefits begins with the written application. Benefit payments may be retroactive for as much as one year before the application date, but no benefits are due until the 6th month following the month when medical conditions caused the person to stop working. Early applications can be seen as evidence of poor motivation to work by Social Security. Thus, the initial claim form should be filed only after an individual’s physician determines that the impairment is expected to last at least 12 months.

Expect to wait

The key to a successful claim is perseverance! Most initial claims are denied. For example, in 2006, only about 40% of initial claims filed in the U.S. were approved. Most applicants who went on to file a written appeal called the “reconsideration” were also turned down (*approximately 20% are approved*).

The third level provides a face-to-face hearing before an administrative law judge – called the ALJ hearing. This level represents the best chance of receiving a favorable decision (*over 50% of the claims are approved*). However, no applicant is entitled to an ALJ hearing until levels one and two have been completed.

A fourth and final level is also available: the Appeals Council of the Social Security Administration. This rarely results in an award of benefits. Beyond this point, a person may file a complaint in the U.S. District Court.

File a winnable claim

To win a claim at any level, the applicant must provide medical evidence of a disabling condition. The best source of this evidence is the applicant’s doctor, not the applicant her or himself.

The law assumes that the treating physician knows the applicant’s condition – and the Social Security Administration gives the greatest weight to the professional findings and opinions. Fatigue, numbness, dizziness and other hidden impairments can be considered by the doctor, so applicants should be sure that their doctor is aware of how their symptoms affect them.

Help is available

To a person who is already having difficulty with daily living, the long application process can look discouraging. Do not give up!

The law permits SSDI applicants to retain a representative on a contingency basis. The fee is based on the outcome of the claim. The representative may or may not be a lawyer but is a professional with expertise in Social Security rules and regulations. This means that SSDI applicants can hire a professional who will file the initial application, secure medical statements from the appropriate sources, and represent an applicant before the administrative law judge. A worker who has been forced to retire because of disability should not fear pursuing Social Security benefits to which she or he is entitled.

National Multiple Sclerosis Society; Gale Group

Young Adult/Youth Support Group

Our group is growing!! We had a great time at the Shoreview Community Center. We made use of the basketball court, weight room and the tropical water park (especially the water slide). Members brought their kids and friends to add to the fun.

Some participated and some sat and visited. We’re working on our next event which will be held in July. Watch for details on our website. Let us know if you’d like to be on our invitation mailing list. ***If you have any questions, call Jeri at (651) 481-8588.***

More Support Group Information on Page 10

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
8600 Fremont Ave. South, Bloomington, MN 55401
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., Bloomington, MN 55425
Meeting times vary.
Bertha Edwards, (952) 707-1299

BLOOMINGTON – **Young Adults**

LFM Office: The Atrium, Suite 135
2626 E 82nd St., Bloomington, MN 55425
Call for meeting times.
Melinda Sykora, (612) 437-1180 or
Jeri Hunt, (651) 481-8588 / hjh55126@comcast.com

EDINA – Edina Community Library
5280 Grandview Square, Edina, MN 55436
(952) 847-5425
Meeting times vary.
Benita Taylor, (952) 829-8063

INVER GROVE HEIGHTS – Khoury's
5660 Bishop Ave., Inver Grove Heights, MN 55076
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, Minneapolis, MN 55409
Call for times and room number.
Angela Williams, (612) 242-8731

SAINT LOUIS PARK – Park Nicollet Medical Center
(Co-sponsored by Arthritis Center)
3800 Park Nicollet Blvd., St. Louis Park, MN 55416
7th Floor West Conference Room
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 Rm.
Karla Lysen, (320) 634-0276

DULUTH – Saint Mary's Hospital,
Oncology Classroom (4th Street Entrance)
Last Wednesday, 7:00 p.m.
No summer meetings (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, Rochester, MN 55901
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, St. Cloud, MN 56303
Fourth Thursday, 2:00 - 3:30 p.m.
Karen David, (320) 393-4206

ST. PETER – Country Kitchen
814 N Minnesota Ave., St. Peter, MN 56082
Third Thursday, 2:00 p.m.
Sue Schott, (507) 246-5247

WILLMAR – McMillan's Restaurant
2620 South 1st St., Willmar, MN 56201
Last Thursday, 2:00 p.m.
Janelle Joneson, (320) 796-5119

Out of State Groups:

BISMARCK, ND – Elks Lodge
900 S Washington St., Bismarck, ND 58504
Second Thursday, 12:00 p.m.
Dave & Jan Jundt, (701) 258-6345

PIERRE, SD – Countryside Hospice, Inc.
200 E Dakota, Suite 100, Pierre, SD 57501
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, Rapid City, SD 57701
Second Saturday, 9:00 - 11:00 a.m.
Nickie Steinback, (605) 721-2864 (please call
before 8:30 p.m.) 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.

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

Faribault: Linda Pansier, (507) 334-2677

Hutchinson: Sheila Mogard, (320) 587-6829

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

Monticello: Nancy Moengen, (612) 295-5965

Moorhead: Rhonda Gilbertson, (218) 287-1924
or rhondagilbertson@hotmail.com

Rochester: Carolyn Hyland, (507) 292-0945 or
curelupus@charter.net

Sioux Falls, SD: Sioux Valley Healthformation,
(605) 333-4444

Twin Cities:

Patty Krageland, (651) 699-2332 and
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

We offer a list of guidelines to
assist groups in running smoothly.
Facilitators have access to these
and you can also request them
from the Foundation office.

For the most up-to-date information, please refer to the Lupus Foundation of Minnesota website, www.lupusmn.org

If you have questions regarding support groups or services, please contact **Timberly Williams** or **John Haffner: (952) 746-5151** or **1-800-645-1131**.

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MARCH 11, 2007 THROUGH MAY 31, 2007

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In Memory of:

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 (given on her birthday, 4/03/07)
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NEW!

The Lupus Foundation of Minnesota is now on MySpace!

Keeping with our emphasis on outreach and awareness, the Foundation has joined the online community of MySpace.

Check us out at:
www.myspace.com/lupusfoundationMN



Schedule of Events

18 Support Groups Meet Monthly
(See page 10 for details.)

July

7 SATURDAY
2007 Summer Festival
Vietnamese Community of MN

11 WEDNESDAY, 11:30 AM
9th Annual Lupus Golf Classic
STONERIDGE Golf Club, Stillwater

12 THURSDAY, 11:30 AM
Conclave Health Fair and Symposium
Minneapolis Convention Center
Kappa Alpha Psi Fraternity
St. Paul/Minneapolis Alumni Chapter

14-15 SATURDAY AND SUNDAY
2007 Dragon Festival

18 WEDNESDAY, 11:30 AM
Buddy Lunch, Lupus Foundation Office: RSVP

23-24 MONDAY AND TUESDAY
2007 SMSC Wellness Conference
LIVING STRONG
Mystic Lake Casino Hotel, Prior Lake
FREE EVENT open to the public

August

15 WEDNESDAY, 11:30 AM
New Client Orientation
Lupus Foundation Office: RSVP

19-24 SUNDAY TO FRIDAY
CAMP SUNSHINE
A retreat for children with life-threatening illnesses and their families
Casco, Maine

September

8 SATURDAY
Annual Lupus Walk for Hope
Minnehaha Park, Minneapolis

15 SATURDAY
Annual Lupus Walk for Hope
Silver Lake Park, Rochester

19 WEDNESDAY, 11:30 AM
Buddy Lunch, Lupus Foundation Office: RSVP

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Your generous contributions will enhance the service mission of the Lupus Foundation of MN!

Store Locations:

- 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 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!

MINNESOTA

The William Flies family dedicates this issue of the Minnesota Lupus News to the memory of their daughter Marette. Marette 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. Please keep us informed of address changes. The Lupus Foundation's phone numbers are **(952) 746-5151** and **1-800-645-1131**. Our web address is www.lupusmn.org