

# PENNSYLVANIA

## L U P U S N E W S

The Newsletter of the Lupus Foundation of Pennsylvania

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## HOW EXERCISE BENEFITS THE IMMUNE SYSTEM

RESEARCH SHOWS 10 MAIN WAYS IN WHICH EXERCISE BOOSTS THE BODY'S IMMUNE SYSTEM TO HELP IT FIGHT OFF ILLNESS.

*By Matthew David Hansen, DPT, MPT, BSPTS*

Many of the health benefits of exercise have been well studied and publicized. For instance, we know that different types of exercise can promote weight maintenance and muscle growth, improve respiratory endurance and cardiovascular health and increase bone density in weight-bearing joints. However, what many people don't know (or at least fail to understand) is that exercise also can improve the immune system.

Years of evidence support the claim that the right amount of certain types of physical activity can promote good health and improve symptoms in individuals with conditions of impaired immunity. Interestingly, the benefits of exercise appear to be similarly evident in persons with deficient immune systems and in persons whose systems are overly active (as is the case with autoimmune disorders). Although science still strives to better understand the exact relationship that links exercise and improved immunity, a number of theories have already been advanced.

Most people accept a few things on blind faith, but knowing how and/or why something works encourages many individuals to find a way to incorporate those things into their lives (assuming it is believed to be important). Exercise is no exception. Yet, to really understand the effects of exercise on the immune system, it's useful to first have a basic knowledge of the system itself.

### THE IMMUNE SYSTEM "STARTING LINEUP"

The immune system is an amazing and somewhat complex system, with the lymph vessels serving as its delivery (or highway) system. Lymph is a semi-clear liquid that carries needed water, oxygen and nutrients that

have been transferred through the blood system (via the walls of the capillaries) to the cells themselves. Together, the lymph and lymph vessels transport uninvited guests and cell waste from the cells and their surroundings to the lymph nodes to be filtered, processed and drained. Lymph nodes are found throughout the body (including the sides of the neck) and frequently enlarge as they respond to new white blood cell production during an infection. For instance, when a person's glands are swollen, there's a good chance that his or her body is trying to fight something. Although any biologist would accuse us of oversimplifying the definitions, let's take a look at some of the major players of the immune system:

*Moderate exercise improves blood flow through the cardiovascular system, thereby helping to flush toxins and germs from the body through the excretory system via urine and sweat.*

**T CELLS.** Most of the cells that make up the immune system are white blood cells. One type of white blood cell, the lymphocytes, includes two major groups referred to as "T cells" and "B cells." T cells have receptors on their surface that interact with molecules (i.e., small particles of a substance composed of two or more atoms) that are found on other cells of the body. By "hooking up" to the molecules, T cells can recognize the matter as something that is supposed to be in the body, or recognize it as a foreign substance or invader like a virus or

# LUPUS FOUNDATION OF PENNSYLVANIA

Landmarks Building  
100 West Station Square Drive  
Pittsburgh, PA 15219

412-261-5886 • 1-800-800-5776

Fax: 412-261-5365

Email: [info@lupuspa.org](mailto:info@lupuspa.org)

Website: [www.lupuspa.org](http://www.lupuspa.org)

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Editor: Marian Belotti

We welcome any subscriber who would like to contribute an article of special interest.

Articles published in all newsletters are of an informative nature and not meant for self diagnosis and/or treatment, nor do they necessarily reflect the views of the Lupus Foundation of Pennsylvania. Lupus varies among patients and medical management must be individualized. If any article stimulates a quest for further information, we advise that you consult with your personal physician.

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\*UPF stands for Ultra Violet Protection Factor. It's a measurement of a fabric's capability to prevent harmful UV rays from reaching your skin. It's similar to SPF ratings for sunscreen.

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# Calendar of Events

May	22	Highmark Walk for a Healthy Community	Pittsburgh
May	22	Highmark Walk for a Healthy Community	Harrisburg
June	5	Highmark Walk for a Healthy Community	Erie
June	8	Daisy Day	Pocono/NE
June	12	Highmark Walk for a Healthy Community	Bethlehem
June	17	"Tee off the Lupus" Tournament	Fleetville
July	5-11	Women's US Open	Oakmont
July	19	Lupus Challenge	Nevillewood
Sept	11	Erie Annual Lupus Loop	Roche Park
Sept	18	Harrisburg Lupus Loop	Carousel Pavilion, City Island
Sept	18	Pittsburgh Lupus Loop	North Shore
Sept	26	Pocono/NE Annual Lupus Loop	Wilkes Barre
Oct	3	Pocono/NE Annual Lupus Loop	Scranton
Oct	9	Harrisburg Lupus Loop	Lancaster
Oct	17	Pocono/NE Annual Lupus Loop	Allentown
Oct		Pittsburgh Education Seminar	tba

Continued from page 1

bacterium. Once an invader is detected, the different types of T cells either work to directly destroy them or work to assist other immune cells in coordinating an attack.

#### CYTOKINES AND CHEMOKINES.

One of the responses that T cells can mount against a trespasser is to secrete cytokines and chemokines. Cytokines are molecules that can activate other immune system cells that are nearby, or signal them to grow or to die. Chemokines are small groups of cytokines that attract more immune system cells to the area of the body where they are needed.

#### B CELLS AND ANTIBODIES.

Certain cytokines released by T cells will activate and direct another type of lymphocyte, the B cells, to make specific antibodies (aka,

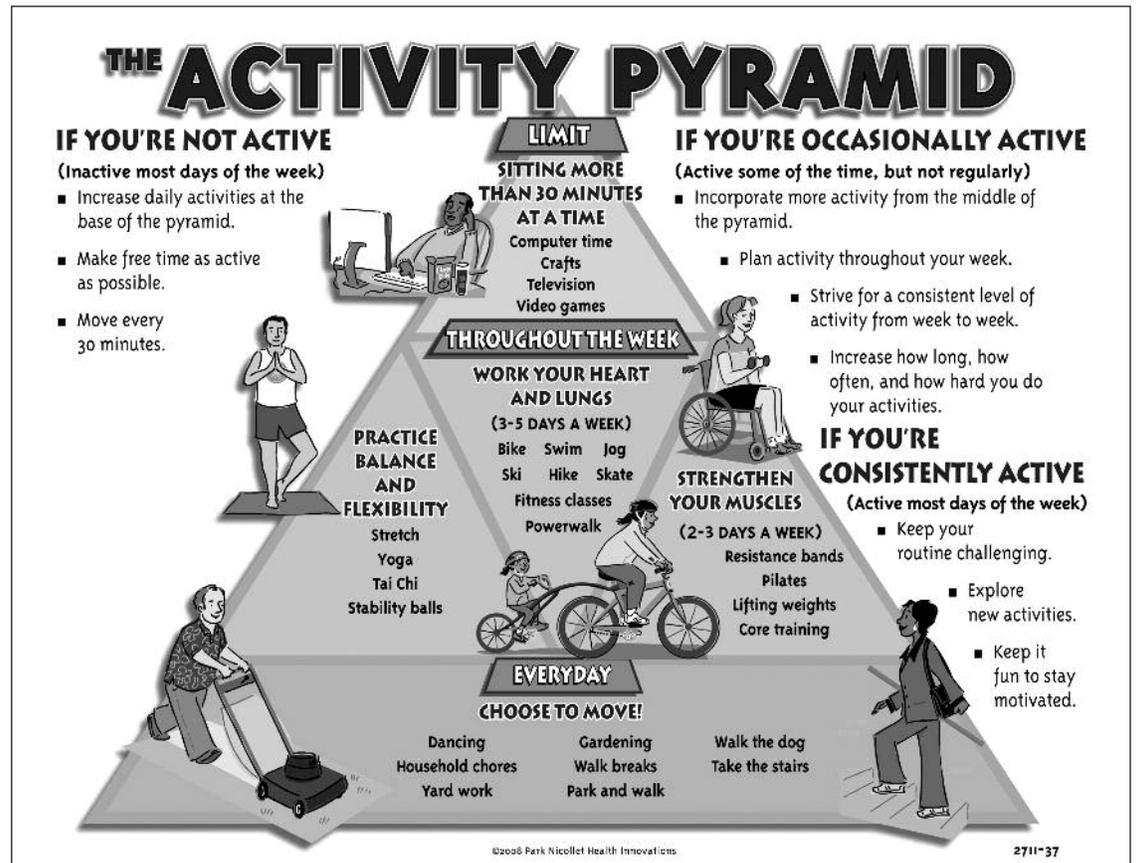
immunoglobulin) against a foreign substance. Antibodies then seek the invaders and bind them to sites on their surface known as antigens. By binding to an antigen, an antibody can either neutralize the foreign object directly or mark it for destruction by other members of the immune system.

**PHAGOCYTES.** Phagocytes are white blood cells that are either stationary or circulate through the bloodstream and ingest harmful substances and dead or dying cells. A certain class of phagocytes, known as "professional" phagocytes (e.g., macrophages, neutrophils, monocytes, dendritic cells and mast cells), also possesses receptors on their surface (somewhat like those found on T cells). Once they have successfully engulfed a foreign invader, they will display part of its remains on their receptor and then present it to other cells of the immune system (including lymphocytes in the lymph nodes) to stimulate a larger response to the infectious agent.

#### BENEFITS OF EXERCISE

Understanding how these players in the immune system work, let's look at 10 ways that exercise might benefit the immune system.

1. One of the most apparent benefits of light exercise is its ability to promote the flow of lymph and the immune cells and antibodies it carries through the body. Unlike the arterial blood vessels, lymph vessels don't have the power of a pump (i.e., the heart) behind them. Instead, they depend on normal body motion, muscle contraction and manual manipulation such as massage to move the lymph along. Deep breathing with stretching (e.g., yoga or tai chi) is another effective exercise for circulating lymph.



The Activity Pyramid ©2008 Park Nicollet Health Innovations. Minneapolis, U.S.A. 1-888-637-2675. Reprinted with permission.

2. Moderate exercise improves blood flow through the cardiovascular system, thereby helping to flush toxins and germs from the body through the excretory system via urine and sweat. Increased blood flow also keeps the antibodies and white blood cells needed to fight infection circulating rapidly as a possible early defense against foreign invaders.

3. When the body is deprived of sufficient oxygen as a result of high altitude, strenuous exercise, impaired breathing or other situations (a condition known as hypoxia), the immune function is impaired. Moderate exercise increases oxygen delivery through the bloodstream, thereby potentially improving the body's resistance.

4. Exercise slightly raises the body's temperature. Although the increase is not nearly as dramatic as running a fever (one of the body's natural reactions against many types of infection), it may still help to kill and/or inhibit the growth of an unwanted aggressor.

5. Scientific studies have recorded a temporary increase in phagocyte activity and function immediately following exercise. It is believed that this increase could take some potentially harmful substances out of the bloodstream before they ever get the chance to travel further. It may also help to boost the fight against an active infection.

6. Regular exercise may help the lungs to rid themselves of airborne viruses and bacteria that are associated with respiratory tract infections.

Continued on page 5



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## Paul Rosen, MD, MPH, MMM



Clinical Director of the Division of Pediatric Rheumatology at Children's Hospital of Pittsburgh of UPMC and Assistant professor of pediatrics at the University of Pittsburgh School of Medicine has offered his expertise to the Lupus Foundation of Pennsylvania

We are pleased to provide this information to those dealing with TEEN LUPUS. Teen years can be difficult—teen years and LUPUS can be very difficult.

Dr Rosen will answer e-mail questions from teens and/or their caregivers. He can be reached at [www.chp.edu/rheumatology](http://www.chp.edu/rheumatology). Under Clinical Services, click on "Ask the pediatric rheumatologist".

Our appreciation to Dr Rosen for offering his expertise to those in need.

## HELP YOURSELF AND THE LUPUS FOUNDATION OF PENNSYLVANIA AT THE SAME TIME.

GoodSearch is a search engine launched in 2005 which donates 50-percent of its revenue to the charities and schools designated by its users. You use GoodSearch exactly as you would any other search engine. Because it's powered by Yahoo!, you get proven search results. The money GoodSearch donates to your cause comes from its advertisers — the users and the organizations do not spend a dime!

In 2007, GoodSearch was expanded to include GoodShop, an online shopping mall of world-class merchants dedicated to helping fund worthy causes across the country. Each purchase made via the GoodShop mall results in a donation to the user's designated charity or school – averaging approximately 3% of the sale, but going up to 20% or even more.

Please view our home page web site at [www.lupuspa.org](http://www.lupuspa.org) for simple directions to become involved. Help the Lupus community in fundraising while searching the web -- you can even view the donations continue to grow.

7. A certain group of cytokines are produced as a consequence of muscle contraction during exercise. One of these cytokines, IL-6, initially promotes inflammation (an important first response of the immune system against infection), but is shortly followed by an increase in anti-inflammatory cytokines. Turning off the inflammation phase is just as important as turning it on; otherwise, tissue and organ damage can occur.

8. T1 helper cells also stimulate inflammation and other changes in the body as a first defense against infection. They are followed by T2 helper cells that produce an anti-inflammatory response. A recent study at the University of Illinois demonstrated that moderate exercise in mice appears to accelerate the change from a T1 to T2 response enough to help combat infection with the flu.

9. Another recent study conducted at Iowa State University found that mice that regularly ran on a treadmill during a period of three and a half months experienced flu symptoms that were less severe than those developed by mice that did not exercise. The study's lead researcher suggested that repeated stress from moderate exercise may improve the body's ability to respond to other types of stress, like those caused by the flu.

## *Even relatively low levels of aerobic exercise can help to boost the immune system.*

10. Speaking of stress, one of the greatest benefits of regular exercise is its ability to help relieve mental and emotional stress linked to suppressed immunity and increased illness. Exercise helps to provide an outlet for nervous energy, take our mind off of our greatest concerns (at least momentarily) and improve our body image. It also reduces the emission of stress-related hormones long thought to suppress the immune system.

### PUTTING SCIENCE INTO ACTION

The 1st century Roman philosopher Marcus Cicero declared, "Never go to excess, but let moderation be your guide." These words should be applied prudently toward many aspects of our lives: eating, drinking, sleeping, working, playing — and exercising! Note that the key to the positive outcomes observed in many of the theories and research listed above is "regular and moderate exercise." In fact, many studies assert that high-intensity or strenuous exercise can actually cause a temporary decrease in the immune system's defenses, referred to as an "open window" period, which can last anywhere from three to 72 hours following the activity. Arduous exercise may also exacerbate other symptoms with autoimmune diseases. Of course, exercising too little or not at all can be just as detrimental to an individual's health.

So, how much exercise is just the right amount? The answer, of course, varies somewhat among individuals, and a doctor should always be consulted first before beginning a new program or before making any major changes to a routine exercise program. However, even relatively low levels of aerobic exercise can help to boost the immune system. Generally speaking, 20 to 30 minutes of a low-impact activity (e.g., brisk walking, light jogging, swimming or biking), three to five times a week, is a great place to start. Regular

moderate exercise appears to have a cumulative effect that leads to a more permanently improved immune response, and again, the benefits seem to be accessible to nearly everyone, regardless of their personal immune status or history.

Several other factors can contribute considerably to the effects of exercise on the immune system and should be considered when planning activities. For example:

- Exercise is discouraged in extreme heat or cold because the changes that are required to help regulate the body's temperature can be stressful to the immune response. Those who live in a cool climate during the winter months should plan more indoor activities like swimming, stationary biking, or walking or jogging on a treadmill (good sanitation techniques should be used when using public facilities). Those who live in a hot climate should try to arrange outdoor physical activities earlier in the morning or later in the evening to escape the heat of the day.
- Exercising at especially high altitudes or in areas of high air pollution should be avoided, because both situations can stress the respiratory system and, in turn, the immunesystem due to decreased oxygen in the air.
- Finally, individuals who aren't feeling well need to be honest with themselves. When ill, the immune system is already under strain from trying to fight the infection. The related stress caused by exercise may challenge recovery. However, for individuals who feel like they are just coming down with something, symptoms are mild and they don't have a fever, there is evidence to suggest that moderate exercise might actually decrease the duration and severity of a mild infection (a doctor should always be consulted for direction).

Remember that there are many benefits of exercise besides those immediately related to an improved immune system. If 20 to 30 minutes of walking is beyond an individual's current ability, there is always something that can be done (see the article, "Exercise and Immune Disease" in the December-January 2010 issue of IG Living magazine). The body's little friends are working hard to maintain well-being — and sending them a big breath of fresh oxygen can only help.

MATTHEW DAVID HANSEN, DPT, MPT, BSPTS, is a practicing physical therapist in Washington state and president of an allied healthcare staffing and consulting agency. He completed his formal education at the University of Utah, Salt Lake City, and has additional training in exercise and sports science, motor development and neurological and pediatric physical therapy.

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# LIFE WITH LUPUS

## KELSEY DENEEN: Dreams for the Future

By Jan Grice

In high schools throughout America, teens are anticipating the end of another academic year and looking forward to a summer of relaxation. The season will bring the pleasures of hanging out with friends, summer jobs, and family vacations. For some, there will be trips to look at colleges; for others, camps away from home. The pressures of the school year subside a bit, though thoughts of the future are always on the minds of young people on the brink of starting independent lives. The teen years are marked by the tension of pulling away from family while craving the security and acceptance it offers. The future is full of many possibilities – possibilities that seem exciting and overwhelming at the same time. For one young 10th grader at Western Wayne High School in Eastern Pennsylvania who dreams of a career in photography and video production, thoughts about what the future may bring must include the possible limitations of a chronic disease. Kelsey Deneen has lupus.



In the spring of 2007, Kelsey Deneen was an ordinary 13-year-old living in rural Pennsylvania, near Scranton, with her Mom and grandmother. Her older brother was finishing his freshman year at Penn State. For Kelsey, the warmer, sunny weather of spring brought not the usual sense of vigor and renewed energy, but a new feeling: pain. The normally healthy Kelsey was suddenly achy and tired. Her joints were swollen; it was hard to walk. Even worse, she had a terrible rash all over her arms. Her mother took her to see the doctor, who thought the rash might be an allergic reaction. Because she was so tired, he thought she might have mononucleosis – a common malady among children her age. But it wasn't mono, and it wasn't an allergic reaction.

Over the next three months, Kelsey continued to feel very ill and made numerous trips to her pediatrician's office. She recalls, "The rash was all over my arms and hands. I'd wear long sleeves to school, but you could still see it on my hands. Once, I was sitting on the table in the doctor's exam room, and my legs turned purple!" For teenagers, fitting in with the peer group is of utmost importance. Anything that marks one as different can be very upsetting. Girls, especially, become focused on appearance. Certain clothes and shoes mark one as "in." Acne becomes a crisis. Little girls who could not be

coaxed into the bathtub now spend hours primping behind closed bathroom doors. At a period when the body is undergoing its own dramatic changes, this focus on the physical is only natural. For Kelsey, the self-consciousness about the rash was mitigated by the support of a strong group of girlfriends. She says with gratitude, "My friends are very supportive of me."

Kelsey recalls the specific day she was given the diagnosis of lupus: Friday, July 13, 2007, only three months after her first symptoms appeared. The day before, she had been released from Hershey Medical Center, still not knowing exactly what was wrong. The family received a call from the doctor, informing them of the diagnosis. Kelsey had never even heard of lupus. She remembers how she felt. "It was very scary." The first year after her diagnosis was difficult. She developed lupus nephritis and was treated with prednisone and immunosuppressants. "I didn't feel well for months," she recalls. She had frequent doctor appointments and missed a lot of school.



Kelsey's mother did all she could to learn about lupus and explain it to her daughter. "She's not one to back away," says Kelsey. "She's always by my side." Her 80-year-old grandmother is very supportive, too. When Kelsey is feeling down, Grandma bakes up a batch of her famous oatmeal raisin cookies – the best medicine! This strong family support is very important for lupus patients. Family

members' willingness to learn about the disease always makes the patient feel less isolated. But when the patient is a child or young teen, it is crucial, especially in managing medications and treatment. By serving as the patient educator, Kelsey's Mom helped her to become an informed patient. Now, at the age of 16, Kelsey is a partner with her rheumatologist, Dr. Catherine Bingham, in managing her disease. "My doctor is great," she says. "She's very supportive, and I'm very close to her." Over the past three years, Kelsey and Dr Bingham have worked together to help Kelsey through the difficult times of getting the disease under control, dealing with complications, and managing medications.

When asked about what things helped the most in coping with lupus, Kelsey cited her experiences at a special camp for children and teens with chronic rheumatic illnesses. For the past two summers, she has attended the one-week "Camp JRA" in

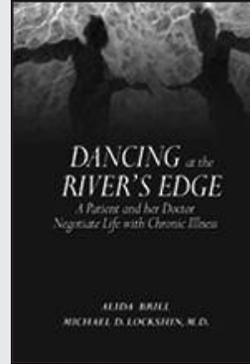
Bloomsburg, Pennsylvania. “JRA” is an acronym for “Juveniles Reaching Achievement.” The camp is a program of the Arthritis Foundation. (see [www.arthritis.org/chapters/eastern-pennsylvania/camp-jra.php](http://www.arthritis.org/chapters/eastern-pennsylvania/camp-jra.php)) Based on a typical summer-camp model, the program allows campers to participate at their ability level and to interact with other children facing similar challenges. Counselors are former campers who share their experiences of chronic illness. Kelsey was a bit reluctant to attend at first. “I had never been to a camp. I didn’t know what to expect, and I didn’t know anyone.” Risking new situations is difficult for any teen, even without a chronic illness. But Kelsey persevered. She bonded right away with her cabin mate: “Now she’s my best friend!” The camp gave Kelsey an opportunity to try new things. “I learned Zumba – it’s a fast-paced dance exercise.”

Recently, Kelsey has been involved with the Lupus Foundation in her area. Because of her experience at Camp JRA, she realizes how important it is to interact with others who have had similar experiences. She is interested in organizing a teen support group where young people with lupus can meet each other and share experiences. “It’s hard because teens don’t really like to talk, so we’ve had a hard time getting them to come,” she says. Kelsey is determined to find a way to solve this dilemma, especially since she knows the benefits of overcoming reluctance. The support group model, which is based on self-sharing, is not ideal for teenagers, who may not have the self-reflective skills that age and experience bring. Because their self-identities are not fully formed, many are embarrassed to reveal their emotions and are afraid of being judged by others. Yet, the experience of facing serious medical issues early in life can, paradoxically, provide the very maturity and self-knowledge that opens one to sharing with others. This has been true for Kelsey. She says that having lupus has made her “a better person.” “I am more appreciative of others. I’ve learned that you never know what others are going through.” Kelsey’s teen support group meets at 1:00 p.m. in the Scranton office of the Lupus Foundation on the third Saturday of each month.

Kelsey is relieved that she has not been “sick, since I was sick the first time.” In other words, she has been stable for a couple years. She is on medication that is keeping her symptoms in control. Yet, she says that she knows that the disease is still there. “I can tell. My body just gets so tired, especially as soon as it gets hot outside.” Like so many other lupus patients, she deals daily with fatigue. She rides a stationary bicycle for 40 minutes each day, but struggles with shortness of breath from asthma. These daily reminders of her physical condition temper her dreams for the future. “I’m afraid of getting very sick again, of a flare. And I wonder if I’ll be able to have children some day. I just worry that something could go wrong.” These are weighty issues for a 16-year old, but ones that Kelsey is able to keep in perspective. She sums up the attitude that keeps her focused on her dreams: “You never know the future. You just hope that everything’s okay.” This is the spirit that will carry her through her week at Camp JRA this summer and support her throughout her life, regardless of what may come her way.

## BOOK CORNER

### Dancing at the River’s Edge: A Patient and Her Doctor Negotiate Life with Chronic Illness



I have encountered no better description of the “autoimmune experience” than when reading *Dancing at the River’s Edge: A Patient and Her Doctor Negotiate Life with Chronic Illness* by Alida Brill and Michael Lockshin, MD. Indeed, crafted from the patient’s and the doctor’s perspective, this book transports the reader to an unusual planet where the rules

of life are changed and the landscape is rife with mystery, uncertainty and unwanted drama. The book presents a starkly contrasting view of the usual concept of illness, where a medical problem is defined, treated and resolved. The shifting grounds of autoimmune illness clearly dominate all aspects of Alida’s long journey, from the very first symptoms that enter her life at age 12 through an endless stream of medical procedures, blood tests, mental health evaluations and second/third/fourth opinions from doctors of all disciplines. Along the way, all of life’s usual events assemble themselves like jigsaw pieces into a picture that ends up only partially resembling that which was on the box.

From the physician’s viewpoint, *Dancing at the River’s Edge* illuminates a journey that is equally trying, as Dr. Lockshin struggles to anticipate and prevent the damaging effects of his patients’ disease when it does not obey the normal rules of medicine. He learns to withhold his jubilation when a patient announces “my illness is gone!” and to orient his practice to accept decades-long relationships that encompass extreme highs and lows. Unlike other physicians who may stand as pillars of control and mastery, he grows to view success as being more about keeping the wolves at bay, than resolution.

Nicely, Alida Brill shared her insights and held a book-signing at the Autoimmune Mysteries conference on May 2 in Scranton. Members of the Lupus Foundation can now purchase the paperback for \$10.00, plus S&H. For more information, contact the Pocono/NE office.

Book Review by Beth Rundell

# VITAMIN D DEFICIENCY AND ITS LINK TO BOTH CARDIOVASCULAR AND RHEUMATIC DISEASE

by Peggy Wu, M.D.

Pittsburgh Rheumatology Associates, Allegheny Specialty Practice Network

Vitamin D deficiency is a key player in both autoimmune disorders and heart disease. Early heart disease is becoming a growing problem in people with autoimmune disorders.

## What is a rheumatic, or autoimmune, disease and what does a rheumatologist do?

Autoimmune disease occurs when the body attacks its own tissues. It is not clear why someone develops an autoimmune disease. One explanation is a genetic predisposition in addition to some other factor such as an infection. To investigate genetic causes, researchers are using genetic microarrays. This technology uses a computer chip to examine someone's genetic material, which may help to develop possible targets for future therapies.

Rheumatologists treat certain autoimmune diseases, musculoskeletal disorders and osteoporosis. There are more than 100 types of these diseases, including rheumatoid arthritis, osteoarthritis, gout, lupus, back pain, psoriatic arthritis, and sarcoidosis. Some of these are very serious diseases that can be difficult to diagnose and treat.

## Is there a link between cardiovascular disease and vitamin D deficiency?

Yes. Increasing evidence supports an association between cardiovascular disease and vitamin D deficiency. Several studies, including one by the Third National Health and Nutrition Examination Survey (NHANES), have made compelling arguments linking vitamin D deficiency and high blood pressure [1], stroke [2], heart failure [3], diabetes, obesity, and high triglycerides (a component of cholesterol) [4, 5]. In addition, vitamin D deficiency has also been associated with abnormalities in the lining of blood vessels and vascular calcification, both of which can lead to early cardiovascular disease [4, 5].

## Is there a link between autoimmune disease and vitamin D deficiency?

Yes. Low levels of vitamin D have been seen in those with autoimmune diseases such as lupus, a disease of young women primarily that can affect many organs, and rheumatoid arthritis. Several studies have shown lower levels of vitamin D to be associated with more active lupus [6]. Similarly, the Women's Iowa Health Study evaluated over 29,000 women and revealed that a greater intake of vitamin D was associated with a lower risk of rheumatoid arthritis [7]. Some studies have also noted lower levels of vitamin D to be associated with more musculoskeletal pain, although evidence on this is controversial.

## Where does vitamin D come from and what causes vitamin D deficiency?

Vitamin D is available in 2 forms --- vitamin D2, which is synthesized by plants, and vitamin D3, which is synthesized by humans through diet or exposure to sunlight. The sun converts a precursor of vitamin D in the skin, and it is then modified by the liver and stored. The kidney converts vitamin D to its active form, which binds to numerous receptors throughout the body. Vitamin D is regulated closely by the kidney, the parathyroid glands, calcium, and phosphorus levels.

Many causes of vitamin D deficiency exist including dietary deficiencies, decreased exposure to the sun, and certain drugs such as steroids and anti-seizure medications. Many people, especially those who are dark-skinned or live in colder climates, are vitamin D deficient. In addition, many patients with lupus are very sensitive to the sun and have to use sunscreen whenever they are outside, therefore increasing their risk of vitamin D deficiency.

## Do autoimmune syndromes have a higher risk of cardiovascular disease?

Yes. Many believe there is an inflammatory component to cardiovascular disease. This may be a major reason why those with autoimmune diseases have a higher risk for early cardiovascular disease. For example, those with lupus have a 5-fold higher incidence of heart attacks compared to the general population, and a 50-fold higher incidence compared to young women [8], the group primarily affected by lupus. In rheumatoid arthritis, cardiovascular events including heart attacks and strokes have been found to occur approximately a decade earlier than in the general population [9] and studies have shown that prolonged treatment of the inflammatory arthritis has helped reduce some cardiovascular events.

## Conclusions

Targeting vitamin D as an additional therapy to prevent cardiovascular disease in those with autoimmune syndromes is reasonable, considering its many functions on the immune system and its associations with cardiovascular risk factors and disease. In addition, vitamin D has anti-inflammatory properties [10].

For more information or to make an appointment with one of the rheumatologists, please contact Pittsburgh Rheumatology Associates at 412-831-1929. We have 2 locations: 9335 McKnight Road, 2nd floor, Pittsburgh, PA 15237 and 2000 Oxford Drive, Suite 113, Bethel Park, PA 15102.

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## LRI National Coalition Thanks Lady Gaga

### Entertainer Speaks of Lupus to Larry King, Raises Awareness

Wednesday, June 2, 2010

The Lupus Research Institute's National Coalition of patient organizations across the country applauds entertainer Lady Gaga for discussing her personal connection to lupus on CNN's Larry King Live. Her courage to speak about lupus makes her a role model for others to publicly discuss this challenging disease and its potentially devastating effects on a family.

In expressing thanks to her fans for their concern about her condition, Lady Gaga brings attention to an autoimmune illness that affects more than 1.5 million Americans-90 percent of whom are female. Her personal encounter with lupus, with her aunt dying young from complications of the disease, reminds us all of the critical importance of research to find less toxic treatments and ultimately a cure.

The LRI National Coalition is grateful for Lady Gaga's outspoken recognition of lupus-an inspiration to her millions of fans and others around the globe-and are here to support all those who have been touched by the disease.

# EVENTS ACROSS



Washington County Health and Safety Fair



Luncheon models at Eleven



Larry Richert, Linda Hudson-Smith, Rudy Smith



Willie Colon & fellow Steelers at the Lupus Luncheon



One of the dozens of beautiful gift baskets Jackie Brubaker created



A St. Patrick's Party for Lupus Patients



Gala Chair Sarah Sturgis with Gala guests

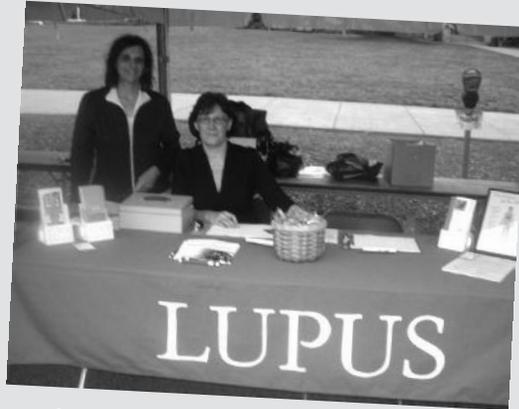
# PENNSYLVANIA



Screening training volunteers for Lupus Alert Day



Henry Lindner, MD and Beth Rundell



8th Annual Highmark Walk for a Healthy Community.



Diane Haberkern and Robert Bohlander, MD



Stacey Proctor, J. Lippincott and Hannah Mierke



Check presentation from Ronin MC fundraiser



Ronin MC fundraiser.

# WHAT'S NEW AT LRI?\*

## Lupus Research Institute Announces a “Breakthrough Decade”: \$100 Million for Innovative Lupus Research

The Lupus Research Institute (LRI)’s pioneering science has generated \$100 million in new research funding for the devastating autoimmune disease of systemic lupus.

“In powering unprecedented scientific discovery, the LRI has forever changed the field of lupus research,” said LRI Board Member Richard K. DeScherer, “LRI scientists have turned \$30 million dollars in initial LRI grant funding into \$70 million more from the National Institutes of Health (NIH).

“An incredible \$100 million dollars for entirely new science in lupus--innovative work that would not exist without the LRI taking risks on the most brilliant scientific minds in the country.”

“The speed with which the Institute has changed the outlook for lupus research is remarkable,” Dr. Paul said.

The LRI selects Novel Research Grant awards based on creativity, novelty, and potential to drive scientific discovery. To date, the Institute has awarded \$30 million to 108 investigators at 55 academic medical centers across 22 states.

More than 65 percent of LRI-funded researchers have gone on to win extended funding from the NIH to further pursue their work.

## Lupus Research Institute Hails Results of CellCept® Trial in People with Lupus Kidney Disease

Persistence pays off as phase III study points to possible new treatment for this often deadly lupus complication.

The Lupus Research Institute (LRI) and its National Coalition of state and local lupus organizations are very encouraged by trial results released by Vifor Pharma, Galencia Group, and Roche demonstrating that the drug CellCept® (mycophenolate mofetil) helps in maintaining remission of lupus nephritis (lupus kidney disease).

After being treated for up to three years, participants in the trial taking CellCept® were able to stave off “treatment failure” for a significantly longer time than those on the “standard of care” drug, azathioprine (Imuran®). Treatment failure was defined as relapse of lupus nephritis, serious renal damage, or death.

“This is a significant finding in lupus research” said LRI President Margaret G. Dowd. “As the organization uniquely dedicated to funding bold approaches to novel research in lupus, the Lupus Research Institute commends the companies for their commitment and perseverance in pursuing this promising therapy, and also thanks the hundreds of people with lupus who enrolled and took part in this important trial.”

# SISTERS HELPING SISTERS

## Sis SLE: Sisters of Women with Lupus Research Study

THE FEINSTEIN INSTITUTE FOR MEDICAL RESEARCH

### WHAT IS THE SIS SLE STUDY?

Autoimmune diseases often run in families. Close relative of people with these diseases are at greater risk of developing the same or another autoimmune disease. The SisSLE (Sisters of Women with SLE) study will allow researchers to understand why some sisters of lupus patients never develop lupus, and if they do, whether there are any factors that precede or prevent the development of disease.

### WHAT ARE THE BENEFITS OF TAKING PART IN THIS STUDY?

You will not benefit directly from giving your blood and DNA for future research. However, your participation may help researchers make discoveries that may benefit people in the future.

### HOW CAN I PARTICIPATE?

The sister with lupus will be asked to answer a one-time health survey and provide a one-time blood sample. The sisters who do not have lupus will be asked to answer a health survey twice-a-year and provide a blood sample once-a-year. The sister's participation is for two years and possibly longer. If you choose to take part in the research study, you can change your mind about your participation at any time.

The blood sample may be collected at The Feinstein Institute for Medical Research in Manhasset, NY, at a lab near your home, or by your personal physician.

### WHO SHOULD JOIN THE SIS SLE STUDY?

WE are enrolling blood-related sisters—one sister with a confirmed diagnosis of lupus and one sister who does not have lupus. If there is more than one sister without lupus, all may participate.

#### CRITERIA FOR THE SISTER WITH LUPUS:

Confirmed diagnosis of lupus; between the ages of 10 and 35.

#### CRITERIA FOR THE SISTER(S) WITHOUT LUPUS:

Currently between the ages of 10 and 35.

### ARE THERE ANY RISKS?

There is a slight risk from having your blood drawn. The main risk to allowing us to store your Protected Health Information (PHI) is the potential for a breach in confidentiality, but we have systems in place to protect your information.

To join this study or get more information, please call a Research Nurse at: 1-877-698-9467 or e-mail: SisSLE @nshs.edu or visit us at: [www.SisSLE.org](http://www.SisSLE.org)

# BRANCH NEWS

## ERIE BRANCH

A New Patient Orientation was presented on Saturday, March 13, 2010 at the UPMC Womancare Center in Hermitage, PA. Thank you to Kim Lombardi and UPMC for providing all that was needed to make the day a huge success. Lupus patients from the Erie Branch who have been diagnosed within the past two years attended with husbands, family and friends. Twenty –one attended and appreciated having many questions answered about lupus as well as the support they received from talking with others with this complicated disease. Many thanks to Cynthia Stone, Linda S. Bauer, and Mary Douthett who presented valuable information, took care of many details and shared their years of experience living with lupus. The Backyard Bistro catered our delicious lunch and we agreed that the orientation would be worth repeating perhaps this summer in Erie.

"We Need GOD not Guns" is the logo of M.A.T.V. or Mothers Against Teen Violence. Sonya Arrington founded this organization in January of this year after the tragic murder of her 19 year old son, Steve, to teen violence. The Erie Branch is thankful for Sonya's valuable part in making the Erie community aware of lupus over the past several years. Understandably her focus has changed in the past few months. The Lupus Foundation is grateful for her help in the past and her continued support of the Lupus cause. The Erie branch of the Lupus Foundation of PA is proud to support Sonya in her efforts to stop teen on teen violence in the city of Erie.

Stacey Proctor and her friend Hannah Mierke used their cosmetology skills to raise funds for the Lupus Foundation of PA

and to make Crawford County more aware of this potentially life threatening disease. Stacey began learning about lupus, through her close friend, Sami Delo. Listening to stories shared by those living with lupus at the Erie branch Lupus Loop last year further inspired this young lady to use her talents to help make a difference. Stacey's Senior project raised close to \$1000 as she and Hannah provided everything from haircuts and highlights to manicures and pedicures along with information about lupus and how it affects those living with the disease. Over a two day period at the Crawford County Career and Technical Center, these two caring seniors worked hard to support their friend in a tangible way. The Lupus Foundation thanks Stacey and Hannah for a job well done and for their challenging example.

The Erie Branch is joining 27 other non-profit organizations in the Highmark Walk for a Healthy Community on Saturday, June 5 at beautiful Presque Isle. There has never been a better time to invest time and energy to raise funds for this worthy cause. We need your help in making lupus a household word by joining us to raise funds thru this walk. You can register on our website or call Jane Lippincott at 866-292-1472 for information or a brochure. Don't miss this great event and opportunity to make a difference for lupus patients.

The Highmark walk is in addition to our regular Lupus Loop at Roche Park which is scheduled for Saturday, September 11, 2010. Save the date and plan to join the fun as the Erie Branch celebrates its 10th annual Lupus Loop. Look for more information to come in the months ahead.

## HARRISBURG BRANCH

They came wearing green hats, green beards, green hair, and lots and lots of shamrocks, but come they did. This past February, despite torrents of icy rain, more than 500 people gathered at a Harrisburg nightclub to celebrate **St. Patrick's Day** and to raise money and awareness for lupus. This 14th annual event, hosted by the Friendly Sons of St. Patrick, also honored Speaker of the House Keith McCall as the 2010 Irishman of the Year. The jolly event also featured Irish step dancers and plenty of food and drink.

The Harrisburg Branch office isn't in Harrisburg anymore! Because so many of the lupus patients served by the Harrisburg Branch visit their rheumatologists at or near the Penn State Hershey Medical Center in Hershey, the **Harrisburg Branch has moved to Hershey**. That's right: the branch office that serves lupus patients in 18 counties of southcentral Pa packed up its array of lupus books, signs, and brochures and moved into its

new space in the "old brownstone" building at 218 W. Governor Road in Hershey. Hershey, a picturesque town with street lights shaped like Hershey Kisses and with the air scented by the fragrance of chocolate bars in the making, is best known as the home of the Hershey chocolate bar and Hershey Park. We hope our lupus patients will enjoy visit us here in the "sweetest place on earth."

Here's all our new contact information:

218 W. Governor Road, first floor

Hershey, PA 17033

Phone: 717--533-0424; Fax: 717-533-0426

Toll-Free Number hasn't changed: 888-215-8787

Please drop by when you can: our office hours remain Tuesday through Friday, 8 to 4.

## HARRISBURG BRANCH NEWS CONTINUED

Our 11th annual **Living with Lupus Gala** on April 10 glittered even more than usual as people gathered at the beautiful Hershey Lodge to enjoy the food, the music, the dancing, and the chance to bid for a staggering array of more than 160 auction items. Channel 27 anchor Valerie Prichett emceed this very special event; the Burning House Band provided the music; and 125 guests happily bid on one-of-a-kind collectibles including an autographed and authenticated photograph from the late Dale Earnhardt Sr., an autographed Miley Cyrus poster, a handmade quilt, and a signed Sylvester Stallone boxing glove. Or, they took home wonderful art, beauty and spa treatments, a night on the town, chocolates, fabulous toys, vacations, hand-crafted jewelry, and extraordinary gift baskets to please all ages and tastes. The evening marked the culmination of a year of hard work by Gala

Chair Sarah Sturgis and her team. The dinner dance was made all the more special by the moving testimony from two lupus patients, Cloei Reisinger and Diane Motter. Diane Matter, who is a quadruple amputee as a result of her lupus, was an incredible inspiration to everyone attending. No one will forget their wonderful evening.

Other lupus fund raisers at the Harrisburg branch include a dress down day at an architectural firm and the Wildtree party. Thanks to all who were involved in so many ways. Staff from the office taped a thirty minute presentation on lupus that is now airing on demand on Comcast. Please view and share your feedback with us. We are working very hard to raise awareness and educate everyone about lupus.

## PITTSBURGH BRANCH

**Women's US Open- Oakmont Country Club--2010 Call for Volunteers.** The US OPEN of 2007 at Oakmont Country Club was a great fundraising opportunity for the Lupus Foundation of PA. We have been invited back for the 2010 Women's US Open. If you joined us (or perhaps missed the opportunity) in 2007, you won't want to miss another chance to be a part of the fun and excitement. Mark your calendar for the week of Monday, July 5th through Sunday, July 11th. This year we are responsible for a "full menu" concession booth located at the entrance. It is a more convenient location for anyone experiencing a problem with the long trek back and forth to our booth at the Men's Open. Consider this an opportunity for a family or friend group activity and feel free to pass this request on to anyone you know who may be interested. Please call the office at 412.261.5586 or email [mtonti@lupuspa.org](mailto:mtonti@lupuspa.org) for available shifts and additional information.

The **Twenty- First Annual Lupus Challenge Golf Tournament** will take place on Monday, July 19, at the Club at Neville wood. Jay Caufield, former Pittsburgh Penguin serves as our Honor Chairman, along with Challenge Chairmen; Tom Miller, Dan and Bill Pietragallo. The Event is held in memory of Kathleen Rooney Miller, Emily Pietragallo, and Lisa King McKean. If you love golf or if your Company is interested in joining us, come out for a day of 18 Holes, Lunch, Cocktails, Dinner and Auction, all for a great cause.

Join Pittsburgh Steelers, Willie Colon and the Outback Steakhouse on Saturday, September 18th at the Great Lawn on the North Shore as we celebrate our **18th Annual Lupus Loop 5K**. Walk, Run, Skate, Raise Pledges, Form a Team and bring out Rover for the Dog Jog as we stand together to raise awareness of Lupus. The Lupus Loop is our signature event across the State, watch for brochures and check out our web site, look for dates and locations in Erie, Harrisburg, Pocono's and Pittsburgh. The Pittsburgh Branch of the Foundation has had the fortunate opportunity to offer original scenes of the city of Pittsburgh, each

holiday season for the past twelve years. The late watercolor artist Jess Hager has donated his original artwork to the Foundation offering us a means of fundraising to promote patient services throughout western Pennsylvania. Watch for a new scene this fall for our **holiday greeting card** and order early, as these limited edition cards sell out quickly.

It was great to see everyone who came out to support our foundation and others on Saturday May 22nd at Schenley Park in Pittsburgh for the **8th Annual Highmark Walk for a Healthy Community**. We are grateful to our participants and especially to Highmark for planning this event, which benefited over 50 nonprofits. WPXI was generous enough to cover the event by lending the talented Peggy Finnegan and crew for the day. Our good friend, Steely McBeem also joined in the fun by cheering on racers and waving hello to diehard Steelers fans. And luckily the rain held off, for once, so that this day could be a great success.

On April 17th, the spring luncheon started out with a chill due to temperatures below 50 degrees. Things did warm up inside as guests began to arrive and forget all about the cold beyond the doors. We are fortunate to have such loyal celebrity guests to facilitate the success of events such as our **32nd Annual Lupus Luncheon**. With emcee Larry Richert to make us laugh during the fashion show and Pittsburgh Steeler Willie Colon with teammates—Max Starks, Matt Spaeth, Kraig Urbik and Trai Essex—to autograph, meet and greet before lunch, we were guaranteed to host an incredible afternoon. The continued support of our sponsors—The Polito and Pferdehirt Family, GNC, and Allegheny Valley Bank—coupled with the dedication of event chair Donna Polito, allowed us to transform a restaurant into a runway. This year our models were draped in the eclectic fashions of Via, Fluid, and Planet Pulse boutiques. We were able to enjoy decadent food during the fashion show served by the wonderful staff at **ELEVEN**, where we were welcomed back for our second luncheon at their restaurant in the Strip District. Our

## PITTSBURGH BRANCH NEWS CONTINUED

event speaker, Linda Hudson-Smith told us her compelling life story of lupus, including the doctor's struggle to diagnose lupus symptoms and her transformation from hobby-writer to national best-selling author. We are looking forward to outdoing ourselves at next year's luncheon and hope to see this success at our upcoming events.

A well attended, excellent **lupus education seminar** was held on April 24th at the new Courtyard by Marriott Shadyside. It was so well attended we were nearly at standing room only status. Evaluations by the attendees were very positive of the three speakers, Dr John Lech, Dr Peggy Wu, and Dr Susan Stollings. We thank them for their willingness to donate their time and expertise to present their knowledge to us. Our next program is currently being planned for a Saturday in October. Please check our website for information – we look forward to seeing you. Life is busy and time is precious for everyone. That is why the Pittsburgh branch offers a **New Patient Orientation** for patients, their families and friends. The session is taught by a registered nurse with experience in lupus education. A five hour program

will provide the beginnings of what you want and need to know about lupus. Subjects include: understanding lupus, doctor-patient relationships, lupus medications, family/social issues, nutrition, exercise, journaling, resources and others. We offer this program twice a year on a Saturday in the spring and fall. We encourage group attendance as this forum promotes interact with other with lupus. Private programs can be arranged on an as needed basis. Studies have shown that the more you know about lupus, the better you do. Please call our office at 412-261-5886 for information about our upcoming date.

Also, for your lupus education needs, a **nurse consultant** is available in our office on Mondays, Tuesdays, and Thursdays. This is provided for those with lupus, families and friends and the community at large including medical personnel. A message can be recorded for the patient services director on other days by calling our office at 412-261-5886. We are here to help you understand the very complex disease known as lupus.

## POCONO/NE BRANCH

Be sure to check the website or call the Branch office for updated information regarding **Alternative Approaches to Symptom Relief**. The office's Resource Center for Autoimmune Diseases has recently added a number of new services to the menu of those available for those suffering from autoimmune symptoms. This is an opportunity to try a technique you may have been wondering about to see if it helps alleviate symptoms, or is something you may find enjoyable – at an affordable rate. Chair massage, Reiki, Reflexology, Yoga, Detox Footbaths and Acupuncture are offered. Providers are in tune to the needs and issues of people with autoimmune disease.

The Pocono/NE Branch, Resource Center for Autoimmune Diseases now offers a number of helpful **Monthly Support Services**: disease-specific support groups, a teen support group, and a men's support group. We also offer several regular workshops including: New Patient Orientation, Introduction to the Disability Process, Gluten Free Information Exchange and "Overcoming Obstacles Creatively" – a workshop-style group guided by an art therapist. No talent necessary! Check the website or call the office for the schedule.

If you would like to receive a **monthly calendar** listing all activities, programs and events organized by the Pocono/NE Branch via mail or email, you simply need to call the office 1-888-99LUPUS to give us your current email address or request delivery by regular mail. We want to keep everyone informed – but we need to hear from you! Let us know if you have and use email and if this is an acceptable method to reach you, because we are increasing use of this technology to convey information whenever possible. However, if you prefer to receive information by mail, we're happy to oblige!

Sincere thanks to Joe Ryzewski for donating a 42-inch flat screen TV for our membership drive. Those who took out a new membership or renewed their membership between April 21 and June 12 were entered to win. The lucky winner was Nancy Ayers - who was thrilled to receive the new TV delivered right to her door!

You may have called the office and heard some unfamiliar voices answering the phone...we have been fortunate to now have assistance from new volunteers, interns and community-service agents. Mary Warnock has been working in the office since the Fall as part of her internship with Bloomsburg University. Mary is pursuing a Master's Degree in Instructional Technology. She has helped to increase the capacity of the office to record educational programs and make copies for those who could not attend. She also has been instrumental in recruiting alternative providers, and creating brochures that explain each technique. Jo Marturano is the new office Receptionist, funded through the Experience Works program. Dee Myers has been assisting with the lending library, the Resource Room and other projects. Debbie Boyle continues her valuable service as nurse consultant and facilitator of the Gluten Free Information Exchange. Thank you to all!

Watch for next year's free wellness workshop series: **Eating Well with Autoimmune Diseases**. Thanks to a grant from the Margaret Briggs Foundation, this workshop series will focus entirely on various aspects of diet and nutrition as they relate to those affected by autoimmune disease. As last year, the workshops will be held each month from September through June – with a recess during the winter - at the Scranton office and at John Heinz Institute in Wilkes Barre. Brochures with topics, speakers, dates, and times of the workshops will be mailed in August.

## POCONO/NE BRANCH NEWS CONTINUED

Did you know we are on Facebook? It's easy to become a "Facebook Friend" of the Lupus Foundation/Pocono Northeast Branch. After you have logged on to your Facebook account, simply type "Lupus Foundation/Pocono Northeast Branch" in the search area in the upper left hand side and our page will come up. Become a friend and our information will scroll weekly on the news feed on your Facebook wall. We list upcoming speakers and programs, support group information and all kinds of interesting facts about the activities of our branch. You may even make a new friend yourself from among those who visit our page. Join us on Facebook!

The **Autoimmune Mysteries** educational conference was a huge success, attracting over 200 people affected by dozens of different autoimmune diseases. Thanks to speakers. Stephen Paget, MD; Dr. Andre Garabedian, MD and Alida Brill, author of *Dancing at the River's Edge: A Patient and Her Doctor Negotiate Life with Chronic Illness*. The afternoon was filled with excellent information and inspiration. If you missed the conference, each presentation was audio-recorded and you can obtain a copy by calling the office. There is a small fee to cover reproduction mailing costs. Alida's excellent book is still available for purchase. Please call the office for more information.

In recognition of Lupus Alert Day, April 1, the Pocono/NE Branch successfully conducted 169 free lupus screenings at 17 different locations throughout the region. It was recommended to approximately 46% to follow-up with a doctor regarding their symptoms. The event was coordinated by Debbie Bertha, outreach coordinator. In addition to providing screenings, the 34 trained volunteers helped raise awareness about lupus and its symptoms; increased awareness of Lupus Foundation services; and obtained additional screening and demographic data. Screenings were also available via the toll-free telephone number for those unable to get to one of the screening sites. We received a lot of publicity from local newspapers, radio stations and even the local news station WBRE covered the story on its evening newscast.

Another wonderful night of Dinner BINGO ala co-chairs Linda Matylewicz and Devon Fawcett and the entire Bingo committee. Beautifully and seamlessly run, the event was a joy for over 340 attendees who enjoyed delicious food, terrific prizes, and camaraderie throughout the evening. Celebrity callers Ryan Lecky, Pedro Gonzalez, Jim Klas and Emcee Michael Neff kept the program interesting and fresh...this has really become an event to be proud of – thanks to all!

**"Tee off for Lupus" Golf Tournament**, presented by Carbondale Nursing and Rehabilitation Center, is set for July 17 at Lakeland Golf Course in Fleetville. This 9-hole course and club house couldn't be a better setting for such a wonderful addition to our fundraising calendar. Committee members Christina Valvano, Kathryn Bekanich, Bob Hawk, and Linda Matylewicz spearhead a very enjoyable occasion, complete with breakfast, lunch, special-hole contests, a basket raffle and prizes for best Captain-and-Mate scores. If you love golf...don't miss it!

Thanks again to Cynthia Donlan and crew for another great year of **Taming the Wolf Festival** in Hazleton. This event is the premier "Friends and Family" event, and an example of what dedication and commitment to the cause is all about. Raising awareness and funds at the same time, these events broaden the reach of the organization and stimulate community involvement. Also organizing Family and Friends events this year have been Kahley Kuzo, a high school student also from the Hazleton area, who conducted **"A Walk Through Spring"** and Ari Kazmierczak, a Scranton High School student, who organized **"Laps for Lupus"**. We really appreciate everyone's help!

Mark your calendar for this year's Lupus Loop 5k Walk/Run in your area. The Lupus Loop is the signature event for the Lupus Foundation, appearing at a park near you.... All across the state this is our chance to stand together in support of friends and family members who are affected by lupus, and to raise awareness and funds for patient programming and research. In our region, events are scheduled as follows:

- Lupus Loop 5K Paula's Walk/Run: Wilkes Barre, Kirby Park, September 26
- Lupus Loop 5K Walk/Run: Scranton, Nay Aug Park, October 3
- Lupus Loop 2010 Allentown, Lehigh Parkway: October 17

You can help make these events a success:

- Participate! Register and receive a long-sleeve t-shirt. Bring your friends and family – enjoy a beautiful day and have some fun together while helping the cause.
- Raise pledges! Use our on-line E-Tools – you won't believe how easy it is! Great prizes have been donated to reward you for your efforts...an overnight stay for 2 with breakfast at a great resort in the Pocono Mountains!
- Enjoy the event itself! Eat, drink, listen to music, and buy a few raffle tickets – why couldn't it be you who walks away with that great basket?

Brochures with more information will be mailed in

August/September – or check our website. See you there!

In our attempts to contain costs, please visit our website often to become aware of updated information.

See [www.lupuspa.org](http://www.lupuspa.org)

No computer in your home? -visit a friend with a computer or your local library.

# COUNTY REPRESENTATIVES

ADAMS	Kristin Hundley	717-337-9226
ALLEGHENY	Branch Office	412-261-5886
ARMSTRONG	Jean Schaeffer	724-548-5932
BEAVER	Sheila Drevna	724-891-2884
BEDFORD	Sally Frear	814-623-5820
BERKS	Melissa Rogers	610-376-5402
BLAIR	Marjorie Snyder	814-944-5911
BUTLER	Rose Hinch	724-283-8811
CAMBRIA	Cathy Ringler, RN	814-242-9787
CENTRE	Melissa Ostroff-Gundrum	814-235-1376
CLARION	Kathy Baker, RN	814-797-5522
CLEARFIELD	Susan Bender	814-342-1889
CLINTON	Teresa Kodish	570-753-8878
CRAWFORD	Linda Bauer	814-382-0230
DAUPHIN	Carol Lupkie	717-564-1170
ELK	Lynn Hoffman	814-781-6493
FAYETTE	Roxanne Ridgely	724-529-2402
FOREST	Donna Confer	814-755-4410
FRANKLIN	Kathleen Rollins	717-264-7099
GREENE	Linda Husenits	724-833-4761
HUNTINGDON	Ruth Hockenberry	814-448-3152
LANCASTER	Tammy Hoover	717-721-1625
LAWRENCE	Elvira Francazio	724-658-7826
LEBANON	Greg Keiper	717-273-2094
	Jackie Brubaker	717-450-3336
LUZERNE	Cynthia Donlan	570-454-1706
	Carol Weaver	570-443-7292
LYCOMING	Beth Good	570-398-1355
MERCER	Lee Gall	724-253-2182
MCKEAN	Mary Dynda	814-362-4546
MIFFLIN	Brenda Fike	717-899-7737
MONROE	Barb Bourgeois	516-582-9719
NORTHUMBERLAND	Nancy Stuckey	570-473-1210
PIKE	Diane Lanthier	(570) 226-4557, Ext. 3016
POTTER	Brenda Bonczar	814-274-8529
SCHUYLKILL	Jackie Ritzko	570-691-6935
SOMERSET	Dolores Wasylczak, RN	814-445-8684
TIOGA	Amy Ogden	570-638-2722
UNION	Sandy Aikey	570-538-5742
VENANGO	Cathy Graf	814-797-2725
WARREN	Dave & Helen Slocum	814-726-8643
WASHINGTON	Lynne Clerihue	724-348-0451
WAYNE	Diane Lanthier	(570) 226-4557, Ext. 3016
WESTMORELAND	Carla Bates	724-797-7936
	Christine Hoke	412-558-1247
WYOMING	Carrie James	570-836-2810
YORK	Denette Reed	717-252-3610
	Deb Downs	717-699-0475
ALLEGHENY, CAMERON, CLARION, INDIANA and JEFFERSON	Contact Pittsburgh Branch Office at 1-800-800-5776	
ERIE and McKEAN	Contact Erie Branch Office at 1-866-292-1472	
COLUMBIA, CUMBERLAND, FULTON, JUARIATA, MORTOWN, PERRY and SNYDER	Contact Harrisburg Branch Office at 1-888-215-8787	
BRADFORD, CARBON, LACKAWANNA, LEHIGH, NORTH HAMPTON, SULLIVAN and SUSQUEHANNA	Contact Pocono Branch Office at 1-888-995-8787	

# STATEWIDE ONGOING MONTHLY SUPPORT GROUP PROGRAMS

## ERIE BRANCH

### CRAWFORD

Wesbury UM Retirement Community  
Cribbs Building – Community Room  
Second Thursday each month 6:30-8 pm  
Contact Jane Lippincott RN 1-866-292-1472  
or Linda Bauer 1-814-382-0230

### ERIE

St. Vincent's  
Fourth Thursday each month 6-7:30 pm  
Contact Janie Lippincott RN  
1-866-292-1472

### MERCER

UMPC Womancare  
Third Thursday each month 6:30-8 pm  
Contact Janie Lippincott RN  
1-866-292-1472

### VENANGO

UPMC Seneca Place  
Third Tuesday each month 1-2:30 pm  
Contact Janie Lippincott RN  
1-866-292-1472

## HARRISBURG BRANCH

### CHAMBERSBURG

Chambersburg Hospital  
Second Monday each month 7 pm  
Contact Kathleen Rollins  
717-264-7099

### DANVILLE

Geisinger Medical Center  
For meeting schedule contact  
Cindy Matzko, RN, MSN  
570-271-6831

### HARRISBURG

New Hope Church  
First Monday of the month 7 pm  
Contact Lucy Blascovitch  
717-545-6565

### HANOVER

Hanover Community Health and  
Education Building, Classroom 2  
Second Thursday each month 1:30-3:30 pm  
Contact Leslie Kiger 717-624-3379

### LANCASTER

Lancaster General Health Campus  
Third Sunday of the month 4:30-6 pm  
Contact Tom Spaeder 717-394-8989

### LEBANON

Lebanon VA Medical Center  
Building 22, 2nd floor - room 219  
Second Monday each month 7 pm  
Contact Jackie Brubaker  
717-450-3336

### MINORITY AWARENESS

Hemlock Girl Scout Council Office  
Third Thursday each month 7 pm  
Contact Debra Browning  
717-657-4767

### SUNBURY

Sunbury Community Hospital  
For meeting schedule  
Contact Nancy Stuckey  
570-473-1210

## PITTSBURGH BRANCH

### AFRICAN-AMERICAN SUPPORT GROUP CIRCLE L

Homewood-Brushton  
Laketon Heights United Methodist Church  
Second Wednesday each month 6 pm  
Contact Mattie Faye Hines  
412-243-3119

### BEAVER COUNTY

St. John's Lutheran Church  
Fourth Tuesday each month 6 pm  
Contact Sheila Drevna  
724-891-2884

### BUTLER

VA Medical Center  
Third Tuesday each month 7 pm  
Contact Rose Hinch  
724-283-8811

### JOHNSTOWN

Memorial Medical Center  
Second Wednesday each month 6 pm  
Contact Cathy Ringler, RN  
814-242-9787

### MONONGAHELA VALLEY HOSPITAL

Healthy Directions  
Second Tuesday each month 1 pm  
724-348-6699

### UPMC PASSAVANT

Third Tuesday each month 7 pm  
Contact Valarie Brown, RN  
412-527-3335

### WEST MIFFLIN

Holy Spirit Roman Catholic Church  
Third Thursday each month 7 pm  
Contact Diane Collins, RN  
412-469-2079

### WESTMORELAND

Jeannette Hospital  
First Wednesday each month 6:30-8 pm  
Contact Carla Bates 724-797-7936  
or Christine Hoke 412-558-12

## POCONO/NE BRANCH

### HAZLETON

Bowl Arena  
Second Tuesday each month 7 pm  
Contact Cynthia Donlan  
570-454-1706

### MOUNT POCONO

St. Mary's Church  
Fairview Avenue  
Third Tuesday each month 7 pm  
Contact Betty Kruk  
570-894-3629

### SCRANTON

Branch Office  
615 Jefferson Avenue  
Third Monday each month 7:15 pm  
Contact Barbara Peters 570-457-1119  
or Barbara Sewack 570-876-4393

### STROUDSBURG

Pocono Medical Center  
Fourth Tuesday each month 5:30 pm  
Contact Barb Bourgeois 516-582-9719

### WAYNE/PIKE COUNTIES

Wallenpaupack Area High School  
Fourth Wednesday each month 4 pm  
Contact Diane Lanthier  
570-226-4557 x3016

### WILKES-BARRE

John Heinz Institute  
Following Wellness Program each month  
Contact Carol Weaver 570-443-7292

## TELEPHONE SUPPORT GROUP

First Wednesday each month -7:00 pm-8:00 pm

Get the latest information, as well as support, without leaving your home. All you need is a telephone. To receive your call-in instructions, contact the Pittsburgh Branch at 412-261-5886 or toll free 1-800-800-5776



# LUPUS LOOP 2010 WALK/RUN



Join the Lupus Foundation of Pennsylvania and "Get Into the Lupus Loop" as we Walk/Run/ and Skate our way around six cities in the State of PA... Help make a difference in the lives of Lupus Patients and their Families and raise urgently needed funds for research, education, awareness and support.

*Our Mission:*  
TO PROMOTE AWARENESS, EDUCATION, SERVICE  
AND RESEARCH FOR THOSE AFFECTED BY LUPUS.



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LUPUS FOUNDATION OF PENNSYLVANIA

Pocono/NE Branch  
615 Jefferson Ave  
Scranton, PA 18510

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LUPUS FOUNDATION OF PENNSYLVANIA

Pittsburgh Branch  
Landmarks Building  
100 West Station Square Drive  
Pittsburgh, PA 15219

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