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PENNSYLVANIA

L U P U S N E W S

The Newsletter of the Lupus Foundation of Pennsylvania

LUPUS AND PREGNANCY

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By Arun Jeyabalan, MD

Systemic lupus erythematosus (SLE) primarily affects young women during their reproductive years. Therefore, family planning, pregnancy, and contraception are key issues for women with lupus.

In the past, women with lupus were told that they should not get pregnant and, if they did, they should consider terminating the pregnancy. This advice is no longer appropriate for the vast majority of women with lupus. With proper care and planning, most women with lupus can have a safe pregnancy with healthy outcomes for themselves and their babies.

Care and counseling should be tailored to the individual woman since the severity of lupus can vary based on which organs are affected, whether the disease is stable or not, and which medications are used. Pregnancy is more likely to be successful when patients have received preconception counseling from an obstetrician who specializes in caring for high-risk pregnancies (a maternal-fetal medicine specialist) and with a rheumatologist who is familiar with the care of pregnant lupus patients.

During pre-pregnancy counseling, women with lupus should be advised about the impact of the following factors during pregnancy:

- Stability of the disease pre-pregnancy
- Safety of medications
- Kidney involvement with lupus
- Presence of antiphospholipid antibodies in their blood
- Risks of neonatal lupus
- Likelihood of additional pregnancy and postpartum complications

DISEASE STABILITY

Women with lupus often ask, "When is the best time to get pregnant?" Pregnancy outcomes are best in women who are at their healthiest. Ideally, lupus should be in remission. A woman should not have had any major flares of her disease during the six to 12 months before trying to get pregnant. To achieve this degree of disease stability, women may need to be treated aggressively during that time period.

Another common question is, "Will pregnancy make my lupus flare?" The best predictor of flares during pregnancy is the stability of the lupus in the months prior to pregnancy. The best way for a woman to prevent worsening of the disease during pregnancy is to have the disease in remission prior to becoming pregnant.

Most flares during pregnancy tend to be mild and can be easily treated. The most common symptoms are arthritis, rashes, and fatigue. Unfortunately, some of these symptoms - mild joint swelling, skin changes, and tiredness - also are associated with normal pregnancy and can make the diagnosis of a lupus flare confusing. Your team of care providers will closely monitor you to help them distinguish whether your symptoms are due to normal changes of pregnancy or to mild lupus flares.

Some lupus flares during pregnancy, however, can be very serious. For example, a flare involving the kidneys is more common in women who have had kidney involvement (lupus nephritis) with their lupus prior to pregnancy. Regardless of the severity, all lupus flares need to be treated promptly and appropriately during pregnancy to prevent more serious consequences.

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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.

STATE NEWS

The Board of Directors of the Lupus Foundation of Pennsylvania is pleased to announce the addition of two new members to the State Board: Judith Rienzi of Clark Summit, representing the Pocono NE Branch and Melissa Franko of the North Hills, Pittsburgh, representing the Pittsburgh Branch. We welcome each of them and look forward to their guidance and contributions in the upcoming years.

FDA Arthritis Advisory Committee Recommends Approval of Benlysta

On November 16, 2010, the U.S. Food and Drug Administration (FDA) Arthritis Advisory Committee voted overwhelmingly (13 to 2) to recommend BENLYSTA® for approval as a treatment for lupus. If ultimately approved by the FDA, BENLYSTA would become the first new treatment for lupus in 52 years.

Planned Giving

Consider Estate Planning and Bequests

Make the Lupus Foundation of Pennsylvania the beneficiary of a gift through trust agreements, life insurance, retirement accounts, and other forms of planned giving. By including the Lupus Foundation of Pennsylvania in your Will, you help ensure support of our important mission—a mission to promote awareness, education, service and research for those affected by Lupus. Also to find better treatments and, ultimately, a cure.

Give Stocks and Securities

Stocks and securities can also be gifted to the Foundation to find better treatments and a cure.

Calendar of Events

January 9	Ski Day for Lupus at Elk Mountain	Uniondale
April	Spring Education Seminar	Pittsburgh
April	Lupus Luncheon	Pittsburgh
April 27	Lupus Dinner Bingo	Dickson City
May 28	Taming the Wolf Festival	Conyngham
June 7	Annual Daisy Day	Pocono/NE

KIDNEY INVOLVEMENT

Poor kidney function because of prior or active lupus nephritis puts a pregnancy at high risk for complications. The level of kidney function present before pregnancy is an important determinant of pregnancy outcome. If kidney function is impaired, as indicated by an abnormally high blood creatinine level, excessive protein loss in the urine, or if blood pressure is higher than normal, several adverse outcomes can be more likely to occur during pregnancy. These complications include preeclampsia, inadequate growth of the baby, and increased risk of premature delivery.

Preeclampsia, also known as toxemia, is a serious pregnancy condition characterized by an increase in blood pressure and excessive protein in the urine. If severe, preeclampsia can involve the brain, lungs, liver, and kidneys, which can be dangerous for both mom and baby. The cure for preeclampsia is delivery of the baby, which may need to occur very prematurely.

When women with lupus have serious complication such as severe preeclampsia, maternal-fetal medicine specialists, rheumatologists, and neonatologists (specialists in taking care of premature newborns) often work together to optimize the outcome for both the mother and her baby. With this approach, the members of the medical care team work together to provide guidance and recommendations to help the lupus patient achieve the best possible outcome with her pregnancy.

ANTIPHOSPHOLIPID ANTIBODIES AND ANTIPHOSPHOLIPID ANTIBODIES SYNDROME

Approximately one-third of women with lupus will have antibodies in their blood that can cause blood to clot in their arteries, veins, and in the placenta. These antiphospholipid antibodies also are known as anticardiolipin antibodies and the lupus anticoagulant. Lupus anticoagulant is a misnomer since these antibodies actually increase blood clotting. When formed, blood clots in arteries or veins can be life-threatening to the mother by causing a stroke or a pulmonary embolism (blood clots in the lungs). Since healthy pregnant women are at slightly higher risk of developing blood clots, women with lupus who have antiphospholipid antibodies are at even greater risk. These patients may need to receive blood thinners during pregnancy.

Antiphospholipid antibodies also may cause blood clots to form in the placenta, affecting its proper function. In severe cases, placental damage can lead to inadequate growth of the baby and, in rare cases, stillbirth. Therefore, lupus patients with antiphospholipid antibodies require close monitoring of their baby's growth and well-being so that any complications can be detected early and/or treated aggressively.

NEONATAL LUPUS

About one-third of women with lupus will have anti-SSA and/or anti-SSB antibodies (formerly called anti-Ro and anti-La antibodies) in their circulation. Although these antibodies can cross the placenta and have the potential to cause neonatal lupus, less than 5% of women will have a newborn affected by these antibodies. Neonatal lupus is not the same as systemic lupus erythematosus. Typically these newborns have a rash and some blood test abnormalities, which all resolve as the antibodies are cleared out of the baby's system in the first few weeks after birth.

A more serious consequence is that anti-SSA or anti-SSB antibodies can affect the pacemaker system of a baby's heart and can lead to an irregular heart rhythm called congenital heart block. This condition, which causes the fetus to have a very low heart rate, is rare and potentially treatable, but is a permanent condition. Because fetuses can develop heart failure in utero, they require close monitoring of fetal heart function by ultrasound, as well as frequent heart rate checks throughout pregnancy. After birth, the neonates should have an evaluation by a pediatric cardiologist. If the low neonatal heart rate persists, the infant may need a pacemaker permanently.

PRENATAL CARE PLANNING

For each woman with lupus, the care plan during pregnancy needs to be based on the severity of the lupus, disease activity, and the various factors mentioned above. The multidisciplinary care team should include at least a maternal-fetal medicine specialist and a rheumatologist who is familiar with caring for lupus patients who are pregnant. Other important members of the team may include the primary obstetrician, a kidney specialist, the primary care physician, a neonatologist, and a pediatrician (for post-delivery care), and family and friends. The health care team needs to pay close attention to any concerns expressed by the patient. Lupus can adversely affect pregnancy, and pregnancy can affect lupus at any stage of pregnancy. These adverse consequences may require major changes in the care plan for the remainder of the pregnancy.

For all patients with lupus, an early ultrasound test is recommended to establish the viability of the pregnancy and to set a reliable due date. Blood tests will be ordered to evaluate kidney function and to determine if antiphospholipid antibodies or SSA/SSB antibodies are present in the patient's blood. A detailed ultrasound examination is recommended at 18 to 20 weeks of pregnancy to evaluate the baby's anatomy. Thereafter ultrasound tests are ordered every three to four weeks in the third trimester to monitor fetal growth. During the last eight to 12 weeks of the pregnancy, patient visits are more frequent, sometimes as often as two to three times per week, so that the health and well-being of both mother and baby can be evaluated as the due date approaches.

LABOR & DELIVERY

The timing of delivery is dependent on how well both the mother and her fetus are doing. Often, delivery prior to or around the patient's due date is recommended. Vaginal delivery is preferred since the recovery is more rapid and there is less blood loss than with a cesarean section. A cesarean section may, however, be indicated for specific reasons and can generally be done safely, regardless of the patient's disease severity.

BREASTFEEDING & POSTPARTUM CARE

In general, mothers are encouraged to breast feed, since breast milk contains unique nutrients and antibodies that are not found in formulas. However, this choice is an individual one based on many factors, most notably the effect on the newborn of any medications that the mother may still need to take after her delivery. An additional consideration is the sleep deprivation that happens to the new mother after delivery, which may increase the risk of lupus flares. Breast pumping, which allows a mother to collect her breast milk and to feed her baby with breast milk, is often a good alternative to nursing. The weeks



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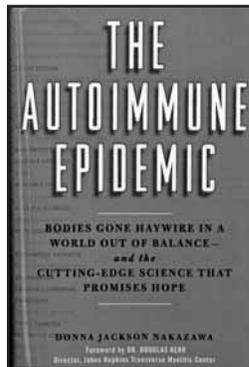
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BOOK CORNER

THE AUTOIMMUNE EPIDEMIC

**Bodies Gone Haywire in a World out of Balance-and
the Cutting-Edge Science That Promises Hope**



By Donna Jackson Nakazawa

“The number of people in the US afflicted with an autoimmune disease is double that of people diagnosed with cancer. Nearly every one of us knows someone whose life has been altered forever by mysterious, chronic illness such as multiple sclerosis, lupus, Crohn’s disease, type 1 diabetes, or rheumatoid arthritis. In these diseases, the body literally turns

on itself in an act of friendly fire, mistakenly attacking healthy cells as it works to protect the body from viruses, bacteria, and other invaders. The first of its kind, this book sheds much-needed light on an escalating medical crisis that, if uncontrolled, threatens to explode into a national epidemic.” So reads the first paragraph of the jacket cover of this book.

Written in 2008, Nakazawa tells the story of the autoimmune epidemic with nearly one hundred diseases cited. She talks of the possible causes, revolutionary preventions, treatments, and cures being researched around the world. Early in the book, she even shares her personal issues with autoimmunity.

A local rheumatologist with Pittsburgh Rheumatology Associates, Dr Peggy Wu comments about the book. “I think Ms. Nakazawa has done a very thorough job researching and writing this book. Her stories and statements are supported with strong evidence and interviews from the same experts we reference as physicians. I appreciate that she has looked into different environmental causes for autoimmune disease because the fact of the matter is we don't really know what causes autoimmune disease. I always tell patients that there is a 2-hit hypothesis regarding the cause of autoimmune disease. The first hit is genetics which we cannot control. The second hit is unknown - whether it is an infectious trigger, trauma, severe stress, chemicals/toxins, etc. She also provides the frustrating and frightening experience of autoimmune disease through her own personal battle with Guillaine-Barre syndrome and other patients' stories ranging from neurological autoimmune diseases to lupus to gastrointestinal ones like Crohn's disease. I think this book would be very educational and enlightening for a patient diagnosed with an autoimmune disease. She gives good suggestions on things that we may be able to control or avoid in our environment and certainly is an advocate for a more 'green' earth.”

Hard back, 328 pages

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Cost: \$25.00 U.S.

after delivery are commonly a time when women are at risk for lupus flares. Postpartum recovery and the rigors of caring for a newborn can contribute to flares. It is important for women to be closely monitored during this time and to obtain early treatment if needed. A new mom's partner, family, and friends can be very important in helping with her postpartum recovery process.

FAMILY PLANNING & CONTRACEPTION

It is highly recommended that women with lupus plan each pregnancy carefully following the guidelines outlined in this review. A woman's health prior to conception can affect her pregnancy, and pregnancy itself can affect a woman's health. Therefore, effective contraception both preceding and following pregnancy is essential for the woman with lupus.

Lupus patients can choose from many different types of contraception, including hormonal contraception such as birth control pills, which contain estrogen and progesterone or progesterone only; intrauterine devices; and barrier methods (condoms, diaphragm). These methods all should be discussed with an obstetrician or gynecologist who specializes in taking care of women with medical conditions.

For most women with lupus, a successful pregnancy outcome is possible. Careful pregnancy planning, individualized care, and close followup during pregnancy is recommended. At Magee-Womens Hospital of UPMC, there is a multidisciplinary team of physicians and health care providers with extensive experience caring for women with lupus. If you or someone in your family or circle of friends has lupus, we would be happy to arrange a consultation to help with informed choices about a potential pregnancy or any other reproductive health issue.

Arun Jeyabalan, MD, MSCR, is director of maternal-fetal medicine outpatient services and assistance professor of maternal-fetal medicine in the Department of Obstetrics, Gynecology, and Reproductive Sciences at Magee-Womens Hospital of UPMC.

Written December 2008

Reprint permission granted by Dr Jeyabalan, MD She can be contacted at 412-641-6361

COMPLEMENT TESTING

Also known as: C1; C1q; C2; C3; C4; Total Complement; CH50; CH100; Total Hemolytic Complement Activity; C1 esterase inhibitor

Formal name: Complement Activity; Complement Component C3; Complement Component C4

How is it used?

Complement tests, most commonly C3 and C4, are used to determine whether deficiencies or abnormalities in the complement system are causing, or contributing to, a patient's disease or condition. Total complement activity (CH50 or CH100) may be ordered to look at the integrity of the entire classical complement pathway. Other complement components are ordered as needed to look for deficiencies.

Complement testing may be ordered to help diagnose the cause of recurrent microbial infections, angioedema, or inflammation. It may be used to help diagnose and monitor the activity of acute or chronic autoimmune diseases such as systemic lupus erythematosus (SLE). It may be tested and monitored with immune complex-related diseases and conditions such as glomerulonephritis (a kidney disorder), serum sickness, rheumatoid arthritis, and vasculitis. When immune complexes form, complement helps to clear them from the blood, temporarily decreasing complement levels.

When is it ordered?

Complement testing may be ordered when a person has unexplained inflammation or edema or symptoms of an autoimmune disorder such as SLE. It may also be ordered when a doctor suspects that someone may have an immune complex-related condition and he wants to check the status of the person's complement system.

C3 and C4 levels are the most frequently ordered, but others, such as C1 inhibitor, may be ordered when other deficiencies are suspected. Individual complement components may be ordered when the total complement activity (CH50 or CH100) is abnormal to help determine which of the components are deficient or abnormal. C3 and C4 are often ordered together as the relative levels are often important.

When an acute or chronic condition has been diagnosed, complement testing may be used to help give a rough idea of the severity of the condition with the assumption that the severity is linked to the decrease in complement levels. Complement testing may also be ordered occasionally when a doctor wants to monitor the current activity of a condition.

What does the test result mean?

Complement levels may be decreased due to a hereditary deficiency (relatively rare) or due to increased consumption. Hereditary deficiency in one of the complement proteins will usually lead to a high frequency of recurrent microbial infections. Decreased complement levels also are associated with an increased risk of developing an autoimmune disease. Both C3 and C4 levels are typically depressed in SLE while C3 alone is low in septicemia and infections caused by fungi or parasites.

If the deficiency is due to an underlying acute or chronic condition, complement levels will usually return to normal if the underlying condition can be resolved.

Decreased complement levels may be seen with:

Recurrent microbial infections (usually bacterial); Autoimmune diseases, including SLE and vasculitis; Hereditary angioedema; Acquired angioedema; Various types of kidney disease, including glomerulonephritis, lupus nephritis, membranous nephritis, IgA nephropathy; Malnutrition; Septicemia; Serum sickness (immune complex disease)

Complement protein levels are usually increased, along with other unrelated proteins called acute phase reactants, during acute or chronic inflammation. These all usually return to normal when the underlying condition is resolved. However, complement proteins are rarely measured in these conditions, compared to the widely ordered C-reactive protein (CRP), and the relevance of their measurement in these situations is not reviewed here.

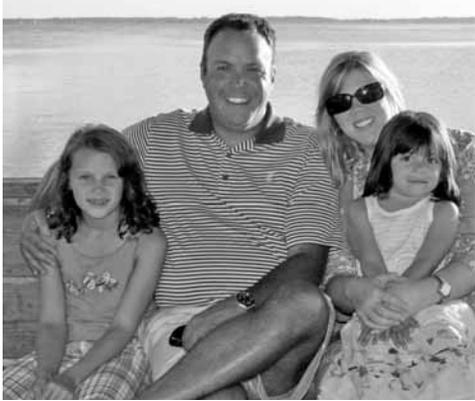
Is there anything else I should know?

Increased and decreased complement levels will not tell the doctor what is wrong with a person, but they can give an indication that the immune system is involved with a condition.

LUPUS AND MOTHERHOOD:

ONE WOMAN'S JOURNEY

By Patricia McAdams



IN THE 38TH WEEK of a mysteriously complicated pregnancy that had left her weak and emotionally and physically exhausted, Peg Kreutzer, 27, was finally about to deliver her baby. Because her labor

had not progressed as hoped, her doctor scheduled her for a C-section. Excited and chatting happily, Peg, her husband Nik, and an assortment of caregivers were wending their way to the operating room for the long-awaited birth.

Suddenly, the baby's heart stopped beating!

"Everyone started shouting," Peg remembers. "They raced me into the operating room and threw me onto an icy cold operating table. There were no explanations.

"I remember screaming and shaking. I remember bright lights. I remember five spinals being jabbed into me — but none worked. I remember someone yelling frantically, 'We have to knock her out NOW.' And I blacked out."

When she awakened, a sweet nurse gently explained that Peg had given birth to a little girl. The baby had trouble breathing, however. She was being moved to a neonatal intensive care unit in another hospital, but Nik wanted Peg to see her first.

"They wheeled the baby to me in the recovery room and I touched her finger. She was so beautiful, but hooked up to so many machines," says Peg. "Nik left with her. I just laid there, alone, and cried."

UNTIL HER PREGNANCY, Peg says she had always enjoyed the best of health. Within weeks of conceiving, however, her health took a dive as she coped not just with severe nausea and vomiting issues, but a series of infections from pancreatitis to bladder and urinary track infections. And then, in her 37th week, a serious kidney infection with a raging fever landed her in the hospital. A week later, the baby was born.

Peg and Nik named their little girl, Julia. And after a worrisome few days, Julia recovered from her breathing difficulties and was

fine. Peg, Nik, and Julia went home to begin their new life as a family a week later.

"I never felt right after that," she says.

Peg, who lives in Lansdale, Pa. recalls the weeks and months following Julia's birth as a blur of aches and pains and exhaustion, all of which she attributed to routine recovery from childbirth. As months turned into years, however, her health grew steadily worse. She developed fibromyalgia and an assortment of gastrointestinal miseries for which she endured one test after another. No one connected the dots, though, considering lupus.

Only Nik and Julia kept Peg's spirits up, she says, with one dream filling her with happy thoughts. As difficult as her pregnancy with Julia had been in 2000, within two and a half years, she and Nik were anxious to open their hearts and home to another child.

"I had always wanted a big family," Peg says, "so I went to a high risk doctor and described my first pregnancy. I asked if my second would be like that too, but he didn't seem too concerned. He said my immune system must have been really low, but they would put me on antibiotics and would monitor me carefully this time. So that's how we were going to proceed."

Unable to conceive, however, Peg went to a fertility specialist. Soon after starting hormone treatments, new health issues arose. She developed polycystic ovaries and was diagnosed with endometriosis, which she treated. When she still did not get pregnant, Peg tried artificial insemination, but the hormones she injected at such high doses triggered excruciating uterine pains for a week. Finally, Peg and Nik said, "Enough. We are done.



"Afterwards I started noticing things. I had many stomach issues and I couldn't keep anything down. I was losing weight — and my hearing, even. And then I started losing my hair! I thought, 'Oh great, now I'm losing my hair too!'"

"Adoption had always been in the back of my mind, because I had a friend growing up who was adopted and I loved the whole idea of it. Nik and I began the adoption process in May 2004.

Piggybacking on all her other problems, Peg awoke one morning with a rash that started on her feet then started climbing up her legs. She went to see a dermatologist. “I’m falling apart,” Peg said, sharing her story. Her dermatologist listened carefully as Peg spoke, putting the pieces of the puzzle together for the first time. Suspecting lupus, the doctor ordered tests confirming the disorder. Peg met with a rheumatologist the next day. Finally, more than four years after symptoms began, Peg started treatment.

Peg’s poor health was not an issue with adoption, she says, because many women who adopt do have some medical issue, which is why they cannot bear children. Women just need a note from their doctor that they are able to parent a child. As it happened, Peg’s rheumatologist and his wife were adopting two children, so he couldn’t have been more supportive.

Peg was juggling a lot at that point, she remembers. She was putting her portfolio together for the adoption and going to classes for that. Julia was in pre-K full time now, too, so Peg went back to work as a full-time guidance counselor. She squeezed in four or five doctor visits every week too, took 22 pills a day, and coped with a huge weight gain and other awful side effects of steroids and the other meds. Then her kidneys started acting up.

“They put me on a chemotherapy drug, but my kidneys were not getting better,” Peg says. “It was looking as though I would have to do the actual intravenous chemotherapy with the possibility of losing my hair and all that.

“At that point my social worker at the adoption agency suggested that we put the adoption on hold for a while. This was an open adoption and the birth parents would be picking us. So if I have a picture of myself looking like I used to in the portfolio, and then the birth mother meets me and I have a scarf on my head, or I’m bald, she would likely feel deceived.

“That was one of my biggest lows,” Peg says. “It was like, I can deal with the weight gain and the nausea and I can even lose my hair, but if lupus was going to prevent me from being able to adopt — that was unbearable.

“And then my doctor put me on Cell Cept— and that has been like a miracle drug. It totally helped. In the end, you hear stories about people dying with cancer or even lupus and you think, okay, so I have to take all these medicines and I have to lose 70 pounds, and I have to go through all this paperwork to prove that I’m a good parent, but you just plug away a day at a time.”

PEG AND NIK were in the adoption book by January 2005. “And then on December 12, 2005, Nik showed up at my school, at our 3:30 p.m. dismissal, with pink roses, to tell me that we were chosen to be the parents of a baby girl, who had been born the night before.”

Peg had known they were being considered by the birth mother for a baby due around Christmas, but didn’t know the birth mother had chosen them. And here was Ella now — two weeks early.

“It was wild. We were totally unprepared. I was running through Babies “R” Us, just throwing things into the cart. Then we raced to the hospital to see Ella.

“She was so cute!” says Peg. “She’s got dark eyes, dark hair and she is so sweet. Julia adores her too. She had begged for a sibling every day for years, and she was very excited to have a little sister.”

In both a positive and negative way, the adoption process was a distraction, Peg says. It was stressful at times, and yet the adoption was her light at the end of the tunnel.



“I used to be a control freak and wanted to plan my life out to the letter,” says Peg, “but there was a different plan and path that we were meant to take. It also helped to put things in perspective. I hear people complain about things, and I know now that these things are just not that important.”

The Cell Cept that she took early on has been effective, but Peg says that Ella has just been her best medicine. “She has brought me such peace and calmness and happiness that I really think that’s when things started to turn around for me with my health. A big piece of lupus is stress, which can definitely trigger these episodes and flare ups. I think also not having to deal with the physical piece of giving birth and the recovery afterwards was a relief.

“Ella landed on my lap, too, so it was just magical that way.”

Peg knows a number of women with lupus who had babies and their pregnancies were traumatic with lots of complications, because hormones are a trigger for some women, as they were for her. But then there are other women with lupus, who do have children successfully, so it varies.

“But adoption is a wonderful option for women to consider growing their families,” says Peg. “The whole journey feels truly like fate. The feeling that we were destined to be together only intensifies in time and it is an emotionally overwhelming feeling.”

TODAY, PEG IS GREAT, she says. She’s been off all of her medications for a while now except for a generic of Plaquenil®, which she takes as a regimen to keep lupus at bay.

Ella and Julia are now four and 10 and are “best sisters,” who still love to bunk together. One single bed is always empty when Peg goes in to check on them, after they have fallen asleep at night.

This article is written for awareness and education about lupus as it is well known to affect everyone differently. Your particular situation must be discussed with Your doctor(s), especially when related to pregnancy.

Patricia McAdams is a medical writer in Kennett Square, Pa. She is a member of the American Medical Writers Association.

2010 closes with a very special anniversary at the Lupus Foundation of Pennsylvania

Thirty five years ago, in 1975, Mrs. Barbara Vandergrift, as a newly diagnosed lupus patient in need of education and support, held the first board meeting of the Pittsburgh Chapter of the Pennsylvania Lupus Foundation in her home. Under discussion during that landmark meeting was the formation of a Medical Advisory Board, fund-raising complement, and the first public meeting that was held November 2, 1975.

Barbara's delayed diagnosis followed fourteen years of inexplicable fever, joint and chest pain and sleeplessness. When these symptoms first appeared in 1958, her physician believed she had rheumatoid arthritis and prescribed medication. Despite her physical discomfort, Barbara continued her work as the executive secretary to the chairman of Gulf Oil Corporation. After giving birth to her daughters in 1963 and 1965, she felt somewhat better and continued to work part-time. Then, in the early 1970's, she experienced a resurgence of her earlier symptoms. A difficult period of hospitalizations and medical treatment ensued, disrupting Barbara's life as she lacked the energy to work and participate in family activities. She was "mystified" with the diagnosis of lupus and found no current medical information; "the resources were old and the diagnosis was always fatal". Barbara recalled, "That was pretty hard to accept, with two children and a career."

She searched out others with lupus in the area, created informational pamphlets, began public meetings and seminars and successful fundraisers. With her advent of the "Local Lupus" newsletter in February 1976, a vital new organ of communication emerged. An innovative and successful fund-raiser, Barbara's early fundraising efforts involved the solicitation of corporate foundation support and the sale of pens, butterfly pins, raffles, flea markets and luncheon benefits. The Lupus Foundation also received a substantial bequest from the charitable trust of Barbara's former boss at Gulf after his death.

It was without bitterness that Barbara recounted what lupus had taken from her life. She was the kind of person who focused on the positive; who saw the glass as "half-full". The years saw the growth of the foundation with Barbara's chapter goal remaining unchanged. She vowed that "we'll never quit until there's a cure."

Today's current objectives reflect her initial vision of a collaboration between the laity and the medical establishment which would promote research by providing financial assistance as well as "allay unfounded fears and serve as a common bond for all those afflicted with the disease." Her years of work with lupus patients had afforded her a unique perspective on coping with this chronic illness. Her advice to patients was to "educate yourself about lupus, submit to the vagaries of the disease and keep going at a slower pace with determination and an acceptance of your limitations. Don't give up, but make adjustment in your activity level when necessary." She urged patients, "don't push yourself and don't try to be all things to all people."

With Barbara's passing, her two daughters have actively taken up the cause. Both Gail Vandergrift and Karen Pool orchestrate and enthusiastically participate in the Lupus Foundation. They keep their mother's mission and memory alive.

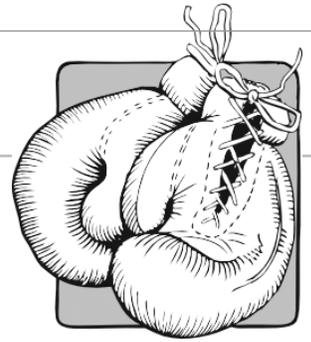
A special Thank you to the Vandergrift family for the Lupus Foundation of Pennsylvania..

Living Lupus*

By Rebecca Lampe RN

The Lupus foundation defines SLE as a chronic, inflammatory disease in which the body's immune system fails to serve its normal protective functions and instead forms antibodies that attack healthy tissues and organs. You can think of it as your body being allergic to itself. For most people, lupus is a mild disease affecting only a few organs but for others, it may cause serious and even life-threatening problems. In other words Lupus is your bodies own inner boxing match against itself. On the good days, you come out the undefeated reining champion and on the bad days, the lupus reins over you with triumph and skill you never knew it had. The person with Lupus bravely ties on their boxing gloves each and everyday for their inner body battle, all while trying to maintain their relationships with others around them.

Close meaningful relationships can be formed between many people such as a spouse, a family member, a friend, a child etc. Just as relationships can easily be formed so can relationships easily be broken, especially when one is under the stress and constant strain of lupus. Loved ones often don't understand that an unattended scheduled function or an unanswered phone call due to illness or overwhelming exhaustion isn't meant to rub the loved one the wrong way or offend the loved one in the slightest bit. Often, to make matters worse, the person suffering from lupus appears "normal" and "not sick" most of the time because the true battle is inside the patient's own immune system where the body secretly attacks itself.



Tips for Dealing with Difficult Relationships:

1. Give a present. Everyone likes receiving a present, so when I was first diagnosed with Lupus I bought everyone, including myself, an educational book on the subject. I suggest going to the website <http://lupuspa.org/bookstore.aspx> to pick out a book from the Lupus organization's selection list.
2. Offer to take the difficult person to your local support group. At the local support group they will meet people with similar stories and see that all Lupus patients don't look "sick". Lupus patients are "normal" people too! If there is a such thing as a normal person in this crazy world.
3. Make an educational date. Attend one of the educational seminars setup by the Lupus Foundation. Education is the key to the disease process.
4. Last of all be patient. Not only are you adjusting to a new lifestyle but your loved one is adjusting to the new lifestyle as well.

Becky works parttime for a dialysis center and a local rheumatologist

* Living Lupus is a column providing helpful information to those affected by the day-to-day challenges of this complex and puzzling disease. It is written for those with lupus, by those with lupus. If you have something you would like to share, please contact the Lupus Foundation administrative office at 800-800-5776.



New Staff members in the Pocono/NE branch(left to right): Susan Smith, Joy Tetlak-Adelstein, Tara Grossi

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

See www.lupuspa.org

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

EVENTS ACROSS



Ashley Sellers and The Wolf Pack were the top fundraising team.



Di Trekkeus Winning Team for Erie Lupus Loop



Debbie Bertha and volunteer Dana Nelson provide information at Cigna Health Fair



Dr Olenak and Dr Green prepare for workshop



Ask the Doctor: Nicole Krajewski, volunteer and Dr. Grady, Rheumatologist meet to discuss 2010 Ask the Doctor in Scranton



State Rep. John Bear reading a citation honoring lupus patients.



Jennifer Long, captain of The Looped Loopers, pauses for a smile with a few of her teammates.

PENNSYLVANIA



Traci Vucish Memorial Golf Classic
Bill Mazeroski and Foursome



Traci Vucish Memorial Golf Classic
Mike Vucish



Sarah Polito and the Shaler School Team
with Willie Colon



Paul Kostyak, Hefren-Tillotson, Loop Sponsor



Honorary Chair, Pittsburgh Steeler, Willie Colon, with
Aunt Joan, Mother Jean and Franko Harris



Little Miss Pumpkin Fest McKenna Mercier &
Tiny Miss Pumpkin Fest Amber Clark at the
Erie Loop



State Rep. Ron Marscio at the Harrisburg Loop

WHAT'S NEW?*

Azathioprine versus mycophenolate mofetil for long-term immunosuppression in lupus nephritis: results from the MAINTAIN Nephritis Trial

Long-term immunosuppressive treatment does not efficiently prevent relapses of lupus nephritis has been studied recently. This investigator-initiated randomised trial tested whether mycophenolate mofetil (MMF) was superior to azathioprine (AZA) as maintenance treatment.

For this study, 105 patients with lupus and proliferative lupus nephritis were included. All received three daily IV pulses of 750 mg methylprednisolone, followed by oral glucocorticoids and six fortnightly cyclophosphamide intravenous pulses of 500 mg. Based on randomisation performed at baseline, AZA (target dose: 2 mg/kg/day) or MMF (target dose: 2 g/day) was given at week 12. Analyses were by intent to treat. Time to renal flare was the primary end point. Mean (SD) follow-up of the intent-to-treat population was 48 (14) months.

The baseline clinical, biological and pathological characteristics of patients allocated to AZA or MMF did not differ. Renal flares were

observed in 13 (25%) AZA-treated and 10 (19%) MMF-treated patients. Time to renal flare, to severe systemic flare, to benign flare and to renal remission did not statistically differ. Over a 3-year period, 24 hour proteinuria, serum creatinine, serum albumin, serum C3, hemoglobin and global disease activity scores improved similarly in both groups. Doubling of serum creatinine occurred in four AZA-treated and three MMF-treated patients. Adverse events did not differ between the groups except for hematological cytopenias, which were statistically more frequent in the AZA group ($p=0.03$) but led only one patient to drop out.

Conclusions Fewer renal flares were observed in patients receiving MMF but the difference did not reach statistical significance. *Annals of the Rheumatic Diseases* The EULAR Journal

Accepted 10 July 2010

New Clinical Test to Predict Lupus Flares Moves Closer to the Market Lupus Research Institute Investigator's Innovative Discovery of a Simple Blood Test for Lupus Flares Now Licensed for Development

New York, NEWYORK—A discovery made by Lupus Research Institute-funded investigator Emily Baechler Gillespie, PhD, at the University of Minnesota has been licensed to a major clinical laboratory for development and could soon result in a test that quickly and easily enables patients and their physicians to determine when a lupus flare is imminent.

Such a test is critical because there currently is no way to predict when a person with systemic lupus is shifting from a cycle of remission, when the disease is relatively quiet, to a cycle of flare, when the disease is active and often very destructive. More than 1.5 million Americans and millions more worldwide suffer from the chronic and unpredictable autoimmune illness in which the body's immune system attacks otherwise healthy tissues and organs such as the joints, skin, heart, and kidneys.

"Through Lupus Research Institute support we ascertained that changes in certain levels of chemokines (proteins) could signal an increased risk of an imminent flare—which is information that could enable caregivers to minimize exposure to corticosteroids (prednisone) and also prevent or lessen flare intensity," said Dr. Gillespie.

Lupus Research Institute (LRI): High Risk to High Reward

It was in 2005 that the LRI took a chance on funding the innovative idea that certain chemokines in the blood might reveal activation of the immune system and signal impending flare. The grant to former University of Minnesota Professor Timothy Behrens (now at Genentech) was subsequently pursued by Dr. Gillespie, an assistant professor.

"This is one of numerous novel and out-of-the-box ideas that the LRI supported when no one else would take the risk," said LRI President Margaret Dowd. "And as documented in our recent LRI Impact Report (Driving Discovery Through Innovation), it's among the many key LRI-funded discoveries poised to significantly improve the lives of

people with lupus."

Dr. Gillespie is among the 20 percent of LRI-funded investigators who are already moving their research discoveries from the bench to the clinic.

Implications for Managing Lupus and Improving Quality of Life

The University of Minnesota's Office for Technology Commercialization granted an exclusive license for the "flare prediction test" in October to Laboratory Corporation of America® Holdings (LabCorp®), which commercializes new diagnostic technologies.

In 2009 Dr. Gillespie reported that levels of chemokines measured at a single visit in 222 patients with mild to moderately active lupus were predictive of the development of a lupus flare over the course of the subsequent 12 months—and then more recently confirmed the findings in a larger group of patients.

In addition to helping to assess lupus activity and aid in making treatment decisions, the test also may be useful in predicting flares over shorter time windows, such as six or even three months, said Dr. Gillespie.

Testing for the chemokines will now be done in additional patients from multiple clinical sites around the country, explained Dr. Gillespie, and ultimately an interventional trial will be designed in which preventative treatments are used in an attempt to reduce the frequency and/or severity of flares in patients with elevated chemokine levels.

Thursday, October 28, 2010 from the Lupus Research Institute

* A word of caution - Remember that no research report is definitive until other scientists have reproduced and confirmed the findings.

PA Fair Care

Pennsylvania's health plan for uninsured adults with pre-existing conditions



www.PAFairCare.com

888-767-7015

(Mon. - Fri., 8:30 a.m. - 4:30 p.m.)

PA Fair Care is Pennsylvania's health plan for uninsured adults with pre-existing conditions. This temporary plan offers insurance for those eligible until federal health insurance reform takes effect in 2014. PA Fair Care is available on a first come basis. So that means once the program is full, we will create a waiting list.



Am I eligible?

To be eligible you must:

- ▶ Be a U.S. citizen or lawful resident
- ▶ Be a resident of Pennsylvania
- ▶ Have a pre-existing health condition
- ▶ Be uninsured for the previous six months

What are the benefits?

Some of the benefits include:

- Preventive care and physician services
- Diagnosis and treatment of illness or injury
- Emergency, accident and medical care
- Prescription medications
- Durable medical equipment

How much does it cost?

The monthly premium is \$283.20 plus additional copays and coinsurance.

How do I apply?

Applications may be completed online at www.PAFairCare.com on and after **Aug 4**.

To apply, you may need your:

- ▶ Social Security Number
- ▶ Driver's License or State ID Number

What documentation do I need to confirm eligibility?

- ▶ Proof of citizenship & identity or lawful residency in the U.S.
- ▶ Proof of a pre-existing condition



www.PAFairCare.com

888-767-7015 (TTY 888-767-7018)

(Mon. - Fri., 8:30 a.m. - 4:30 p.m.)

BRANCH NEWS

ERIE BRANCH

Life is busy for all of us and within nine weeks we'll be welcoming a New Year and cherishing the memories of 2010. It's hard to believe how quickly the days of summer turn into cool, crisp and colorful autumn. As another year comes to an end many of us evaluate the things that were accomplished and consider how our lives have really made a difference. No matter who we are our lives impact our world and the lives of other people.

Since the weather in the Northwestern counties isn't always safe to travel as the winter arrives, we will meet before the weather gets really bad as a large group. We will also be able to stay connected thru the snowy months by using the phone lists provided for each support group. If you don't have a Support Group list for your area, please call Jane Lippincott at 866-292-1472 to receive one in the mail.

Businesses in the Erie area impact Lupus patients in significant ways and the foundation, patients and families are grateful. The Meadville Federal Credit Union collected funds for the Lupus cause in September and contributed over a thousand dollars to those living with this puzzling disease. Union Latina, a group

of Allegheny College students, has chosen the Lupus Foundation as the charity that they would focus on for this year. Their help was invaluable in assuring that the Lupus Loop was a huge success. Thanks to the many faithful companies and individuals who work hard and give generously to make this annual fund raiser an event worth attending each year.

Approximately 110 people attended the 10th annual Lupus Loop at Roche Park in Vernon Township on Saturday, September 11, 2010. It was a beautiful day with many new faces and lots of enthusiasm. Diane Rehberg's Team, Di Trekkers took home the top team prize for 2010 since they raised over \$1000. Donna's Desperados and the Pumpkin Fest Power Teams came in second and third raising over \$600 each. Jean Marie Ryan was the top individual prize winner with \$560. Congratulations to all who participated and helped make our 5K Walk a memorable day.

In these difficult economic times, we still have much to be thankful for. May you and yours remember the blessing of 2010 and look forward to allowing your life to touch the lives of others in positive ways.

HARRISBURG BRANCH

From our new office in Hershey, PA., we enjoyed a beautiful fall in southcentral PA, with the sun shining on each of our outdoor events. How lucky can you get!

Over Labor Day weekend, we joined the over 4000 gathered for a baseball game in Lancaster's Clipper Stadium. Channel 8 News Anchor Ron Martin threw the first pitch on behalf of lupus. Then, on the main concourse of the stadium, we offered lupus information, a chance to win raffle prizes, and an opportunity to register for our fall Lupus Loops.

Two weeks later, we hosted our Harrisburg Lupus Loop on City Island, a beautiful spot in the middle of the Susquehanna River. Our scenic Loop took us around the island, over a bridge, and back again. Channel 8 News Anchor Jim Sinkovitz served as emcee, and State Representative Ron Marsico as our chair. Rep. Marsico won our hearts forever with his personal delivery of gourmet coffee for all. At the Harrisburg Loop, Lindsey McGaughran of the Lupus Ladies team was our top fundraiser, and she won a gift certificate to the Hershey Hotel Spa. In addition, Lindsey's team was the top team fundraiser, and they'll all share in a gift certificate to a new restaurant at Hotel Hershey. During the Loop, Dr. Lisa Scalzi, a rheumatologist at Hershey Medical Center, manned our patient education taking questions one-on-one with lupus patients, who so valued the chance to speak to her.

Come October, we were back at Lancaster's Clipper Stadium for the Lancaster Loop. About 130 participants – our largest crowd ever for the Lancaster Loop – raced and walked around the stadium, and Dr. Rebecca Shepherd of Lancaster Rheumatology kindly took her place as our doctor taking questions about lupus. Ashley Sellers, captain of The Wolf Pack, took the top team prize. Ashley also made jewelry, adding sparkle to our sales table. Leroy Martin took the top prize as an individual fundraiser, and this lucky man will soon be enjoying the Spa at the Hotel Hershey. To kick off the event, State Rep. John Bear, our chair, spoke about why he works to help all who struggle with lupus, while Channel 8 Anchor Ron Martin kept everything moving as our emcee.

Many thanks to everyone who worked so hard to make all these events so enjoyable! We could not have done this without you!

Looking ahead, we're planning an online fundraiser with Gena Hudson of Wildtree Foods, a billiards tournament at Moose Lodge 761 in Carlisle on Feb. 3, 4, and 5, and the Looped Loopers of Lancaster are working on a pub crawl for spring. Meanwhile, State Rep. Bear is working on a lupus documentary with us, so please stay tuned!

PITTSBURGH BRANCH

Another informative education seminar was held on October 16th, at the Holiday Inn in Monroeville. Volunteer speakers included Dr. Fotios Koumpouras, Dr Carol Congedo and Juliette Hale sharing their respective lupus knowledge and support to those in attendance. Entitled Lupus Q & A, the program provided answers to the many questions about lupus and diet, medication, fatigue, pain, job, and living with a chronic disease. These programs are provided twice a year, in the spring and fall, so plan to join us for the next program to learn more. Check our web site for the spring agenda after the new year. Education is key to living with the complex aspects of lupus.

Receiving a diagnosis of lupus can be a confusing, upsetting, and fearful time. To help with these issues, Lupus Orientation provides an overview of lupus, including treatments and socialization with others managing this disease. It is open to anyone newly diagnosed and their families and friends. Our next session will be Saturday, April 30, 2011 at our Station Square office in the South Side with the session starting at 10AM and concluding at 2:30PM. For more information, contact our office at 412-261-5886.

The **21st Annual Lupus Challenge Golf Tournament** was held on July 19th at the Club at Nevillewood and after 20 years continues to be a great success. The weather was beautiful as was the course and a full field of golfers came out in support of a great event dedicated to the memories of: Lisa King McKean, Kathleen Rooney Miller, and Emily Pietragallo. The event is graciously Chaired by family members Tom Miller, Dan and Bill Pietragallo and our ever-faithful Honorary Chairman, Jay Caufield, Pittsburgh Penguin Alumni. The continued success of this event is due to the generosity of Event Sponsor – The Pittsburgh Steelers and two contributing Tournament Sponsors: **The Traci Vucish Memorial Golf Outing**, held on September 20th at Meadowink Golf Club in Murrysville PA. This annual event is held in memory of Traci Vucish by her parents Mike and Valerie Vucish, brother, Mike Vucish, sisters Lori Albright and Cari Simpson, and their families.

The event is unique as it hosts many supporters from the Pittsburgh Pirate Alumni and the Western Pennsylvania Music Industry. **Freddie's II Restaurant and Lounge**, played host to their 5th Annual Lupus Golf Tournament, held September 13th. This event sponsored by Freddie's II is made possible by the generosity and hard work of a core group of dedicated committee members: Ron Kragnes, Patty Dagnal, Andy Burnes, Bob Barrett, and Bill Hurley of the Pittsburgh Steelers Alumni.

The **18th Annual Lupus Loop** was held on September 18th. **"Team up to tackle lupus"** was the special request of our Honorary Spokesperson and Pittsburgh Steeler, Willie Colon. Willie, in honor of his mother Jean Davis, and Event Chair Melissa Franco, in memory of her mother Billie Jo Franko worked hard to support and promote this event. We thank all who responded by their participation in this very special and powerful event in support of the fight against Lupus. All was made more eventful by the supporting appearance of several current Pittsburgh Steelers and a surprise visit to Willie's Mom, Jean, by Steeler Alumni Franco Harris. Thank you to our Presenting Sponsors: Hefren-Tillotson and Outback Steakhouse, as well as to our Committee, Volunteers, Teams, and Participants. Please plan to join us in the fall of 2011 for this fun filled family event

The **Jess Hager Holiday Card Collection**, Pittsburgh scenes continue to be favored and sought after each year. Jess's beautiful artwork and his extraordinary generosity have combined for a successful ongoing fundraising source for the foundation. We are honored to be able to reproduce the scenes he loved so much and are extremely thankful to his family for their continued support of his endeavor.

Be on the lookout for the **33rd Annual Lupus Luncheon** date announcement. The event will be held, once again, at ELEVEN Contemporary Kitchen in the Strip. Look for your invitation in the mail and announcements via email. Information and registration will also be available online at www.lupuspa.org.

POCONO/NE BRANCH

It's an exciting time at the Pocono/NE Branch as we welcome 3 new staff members to the Branch office team. Susan Smith has come on board as Community Programs Coordinator. Susan will be focusing on patient programming and events in the Lehigh Valley as well as other underserved areas throughout our region. Tara Grossi will be our new Development Specialist partnering with Janice Liddic, Events Coordinator, to maximize established events and evaluate new opportunities. Joy Tetlak-Adelstein will serve as Patient Services Coordinator, overseeing patient programs and support services. Joy is a licensed dietician and will also be able to share her nutritional expertise with those who need it. All have extensive backgrounds in nonprofit management, development and patient services and are sure to bring fresh insight and energy to Pocono/NE Branch operations.

We extend a fond farewell to Debbie Bertha, who served as Outreach Coordinator, as she moves on to another opportunity. Debbie did a wonderful job for the Branch submitting publicity, representing the Lupus Foundation at health fairs and employee wellness events and overseeing the Lupus Alert Day screening program. Her husband, Mitch, also helped enormously with Branch computers and IT issues for several years. Thanks to both!

New Branch Council Chairperson Devon Fawcett has hit the ground running with new ideas for member involvement and heightened participation in the mission of the Lupus Foundation. Devon and her family recently served as honorary chairs of the Scranton Lupus Loop, and Devon competently shares her passion for the cause at every opportunity. As Branch Council chair,

POCONO/NE BRANCH NEWS CONTINUED

Devon hopes to define better what Council members can do for the Branch, and to form committees to mobilize the talents of each individual. Devon offers inspired leadership and welcomes those who would like to contribute in the effort to move the Branch forward to join the Branch Council team. If you are interested in serving as Branch Council member, please call to find out the meeting schedule.

The Eating Well with Autoimmune Diseases wellness workshop series is currently underway. Fall workshops featuring some of the top professionals in the region was extremely well received by both Scranton and Wilkes Barre audiences. Thanks to Marilyn Ksiazek, Teri Maldonato, Heather De Luca, Arelene Felccia and Mary Ehret for providing terrific information about diet and nutrition specific to autoimmune patients. After a winter recess, workshops will start up again in March. Be sure to mark your calendar! Workshops are held at the Lupus Foundation office in Scranton and at the John Heinz Institute in Wilkes Barre. There is free parking in both locations. Programs begin at 6 PM.

March

Eating Gluten-Free: Everything You Need to Know

Thursday, March 10 - Scranton Wed, March 16 – Wilkes Barre
Laure Stasik, MS, RD, BSN, RN, CDE Laure Stasik, MS, RD, BSN, RN, CDE

April

Healthy Weight Control: Considerations for those with Autoimmune Disease

Thursday, April 14 - Scranton Wed, April 20 – Wilkes Barre
Theresa Kovacs, Psy.D. Joy Armillay, Ed.D, RD, LDN

May

Are there Supplements, Vitamins, and Herbs that Benefit those with Autoimmune Disease?

Thursday, May 12 - Scranton Wed, May 18 – Wilkes Barre
Maria Wansacz, ND, L.Ac. Maria Wansacz, ND, L.Ac.

June

Managing Co-Existing Diabetes

Thursday, June 9 - Scranton Wed, June 15 – Wilkes Barre
Ruth Wimsatt Jones, MS, RD, LDN Sandy Korpusik RN CDE

If you are not able to attend an educational program, but you would like to hear what the speaker has to say, be sure to ask us about our educational CDs. Most presentations are audio recorded and available on CD for you to listen to at your leisure. Pop them in your car CD player and enjoy while you do your errands! We have a listing of all presentation topics, and would be happy to send or email you the list. The price of each CD is \$4 for members of the Lupus Foundation with an additional \$1 if you would like to have it mailed to you. Did you miss Alida Brill's presentation last year at the Autoimmune Mysteries conference? We have it on CD – she has a wonderful, powerful message! And there are many more....check it out!

Mark your calendar!!! The next annual autoimmune disease conference in Scranton will be April 10. This year's conference **Autoimmune Disease: What a Pain!** will focus on traditional and

complimentary approaches to autoimmune-associated pain management. Keynote speaker Dan Handel, MD, currently with NIH, is a world expert in the area of pain management. There will also be an on-site provider fair to meet local providers and pick up information about various avenues that may be helpful in alleviating pain.

Tee-Off for Lupus sponsored by Carbondale Nursing and Rehabilitation Center was a great success this year. Chaired by Christina Valvano with help from Kathryn Bekanich and other committee members, the 9-hole tournament at Lakeland Golf Course was beautifully executed and enjoyed by all golfers. A wonderful lunch donated by Roseanna's Pizza, terrific prizes throughout the morning and sunny weather combined to make the event a sure winner, no matter how long the putt! Thanks to all involved!

Lupus Loop 2010: Allentown, Scranton and Wilkes Barre.

The weather was absolutely beautiful for every Pocono/NE Branch Lupus Loop – how could we be so lucky? Wonderful friends returned, and new supporters joined the effort to support those with lupus. There are so many people to thank, but special mention of all committee members involved in organizing individual Loops is surely deserved: Jeanie Mikush and the entire Paula's Walk committee, Linda Matylewicz, Wendy Rosetti, Christina Valvano, Debbie O'Boyle, Marilyn and Henri Deutsch, Barb Neff, Tammy and Ryan Brown, Kelsey Deneen – each played an important role in getting the work done and making the Lupus Loop a wonderful experience for all participants. And of course no success would be possible without all the sponsors, teams, individuals, runners and walkers whose efforts and goodwill combined to maintain the vitality and spirit that these events are known for. The Loops are an important part of our fundraising calendar, and their success directly transfers into the quality patient programming the Pocono/NE Branch is known for. Thanks to all!!!!

Would you like to recognize a loved one or special occasion while lending support to the Lupus Foundation, Resource Center for Autoimmune Diseases?

A DAY AT A TIME allows you to CHOOSE ANY DAY or WEEK of the year to name in honor/memory of someone or a special event/occasion. Your donation will be featured on a big calendar in the lobby of the Resource Center, on the monthly program calendar and in the Yearbook/Resource Directory.

Recognize a birthday, anniversary,
or any other special event – a great gift idea!

2011 Yearbook/Resource Directory: reserve your space for a business ad or a "Best Wishes" & "In Honor/Memory" ad. Due to be printed in March, the yearbook will be distributed at Lupus Dinner Bingo, the annual conference and throughout the NEPA throughout the remainder of the year. Becoming more and more popular, the Yearbook consolidates an array of information about lupus, the activities of the Lupus Foundation and business/supporter ads. Be a part of history!

Lupus Word Scramble

Find the lupus-related terms from the list at the bottom of the page.

R L C F N V N N P F N W P J G Q V F U L S N H
 Y L Y B E B D Y G R L L W P L A Q U E N I L S
 F O T S G X U Z V A E A R F F T R O P P U S A
 P W O T I H Y F N U C E R A T B J F Z E S W R
 H Q X N T S H T R N S Y T E E E T A B N K D U
 O Z A I N V I I O E S I Y D L D I S C O I D A
 T F N O A B S P A P G N L E O I C J S S C O H
 O U E J O Y Z R O U C J S R I W S J T I L V F
 S L O D Q Z C I E Y V L U M V W P A E N M B M
 E C I J C H B J X L L H M A A R T N R D W C D
 N E Y C Q R A K Y E Z U E T R X Q E O E C E N
 S R S L E C U B C L N D V O T K I M I R S L E
 I S Y C F L Q T Y E U O E L L N M I D P U L U
 T I S F E R L G E C R S J O U A U A S U P S R
 I T T A P R E C A S V V V G E S R P W F U S O
 V I E N J H U T E F I Q P I W P A L S E L N L
 I L M Q D V I Z T P A C W S D I N A E V S I O
 T U I I L O I M I U T H R T E R S T L E T E G
 Y C C A N R V A V E B B D E U I V E A R R T I
 N S C I T E N E G K S L C E X N Z L M C E O S
 U A F X T N E M N O R I V N E E Z E E D S R T
 M V I N F L A M M A T I O N Q Y C T F S S P G
 Y I S M O T P M Y S S Y E N D I K S G M F H P

ANEMIA
 ANTIBODIES
 ANTIGEN
 ASPIRIN
 BCELLS
 BIOPSY
 BUTTERFLY
 CELLCEPT
 CYTOXAN
 DERMATOLOGIST
 DISCOID

EDUCATION
 ENVIRONMENT
 EXERCISE
 FATIGUE
 FEMALES
 FEVER
 FLARE
 GENETICS
 IMMUNE
 IMURAN
 INFLAMMATION

JOINTS
 KIDNEYS
 LUPUS
 NEUROLOGIST
 PHOTSENSITIVITY
 PLAQUENIL
 PLATELETS
 PLEURISY
 PREDNISONE
 PROTEINS
 RASH

RESEARCH
 SEIZURE
 STEROIDS
 STRESS
 SUPPORT
 SYMPTOMS
 SYSTEMIC
 TCELLS
 ULCERS
 ULTRAVIOLET
 VASCULITIS

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BUTLER	Rose Hinch	724-283-8811
CAMBRIA	Cathy Ringler, RN	814-242-9787
CENTRE	Melissa Ostroff-Gundrum	814-235-1376
CLARION	Kathy Baker, RN	814-221-8407
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, 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 Monday 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
Call 558-2008 for meeting time

WILKES-BARRE

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

WILLIAMSPORT

Call 1-888-99LUPUS
for meeting location & time

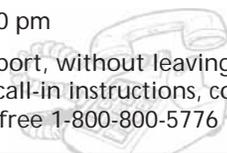
ALLENTOWN

Call 1-888-99LUPUS
for meeting location & time

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



CELEBRATING LUPUS AWARENESS



As a Coalition Member of the Lupus Research Institute, we celebrate S.L.E. Lupus Foundation's 40 years of caring for those affected by lupus. Their Life Without Lupus Gala 2010 in November at Lincoln Center culminated with the signature lupus awareness **ORANGE** lights illuminating the **Empire State Building!** What a great way to promote awareness and education about lupus!! Can you imagine the conversations that ensued when New Yorkers asked why the building was aglow in **ORANGE?**

The Lupus Foundation of Pennsylvania likewise is celebrating an anniversary of service to our community. In 1975, the grass roots start began. The story in its entirety is included on page 8 of this newsletter. We are 35 years strong and working hard for the lupus patients, families, friends and the general population to learn and promote awareness about lupus.

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

LUPUS RESEARCH INSTITUTE
National
Coalition
The Patient Voice for Lupus Research



LUPUS FOUNDATION OF PENNSYLVANIA

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

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