

# Living Well

WITH LUPUS

The Mission of the Lupus Foundation of Colorado (LFC) is to improve the quality of life for people living with Lupus by advancing community education and awareness; by providing patient and family services; by promoting research for the prevention, early diagnosis, effective treatment, and discovery of a cure for the disease; and by advocating for patients, family and community.

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Fall 2011

Sandra Kanowitz, Editor

The Lupus Foundation of Colorado believes that no one should have to suffer in silence from a disease that so few understand.

You have the opportunity to help LFC continue to change the face of lupus in Colorado. As a small organization, with a 40 year history of providing education, advocacy and support to the 20,000 Coloradans living with the disease, we cannot fight lupus alone! Now is the time for each and every one of you to voice your support by making a contribution to this year's annual appeal. No amount is too small.

Together we can make 2012, the 40th anniversary of LFC, a banner year.

As loyal subscribers and readers of this newsletter, you better than most understand the importance of keeping up with new developments and research into the disease. The annual contribution to research made by LFC reflects our commitment to finding a cure for the disease by supporting innovative research. You know that continuing education via teleconferences and seminars makes a critical difference in your personal wellbeing. You recognize the value of Peer-to-Peer support provided via our telephone and support group network. LFC is the only organization in Colorado that provides emergency assistance for those in need of financial help with prescriptions,

medical bills, medical equipment and a host of other needs. And, you appreciate the difference that comes from reading this newsletter and



*LFC, MS and MCPN were recently recognized for their commitment to client advocacy by the Colorado Consumer Health Initiative.*

knowing that you are not alone in your fight against this difficult disease.

What separates LFC from many other organizations has been a commitment to long-range planning that has made the organization financially solid, adept at weathering tough times and able look down the road to a strong future. However, there is no question that the current and increasing demand for services taxes all of our resources.

This newsletter contains a special envelope to make sending a gift easy. Your thoughtful consideration will be deeply appreciated by all those who come to the Lupus Foundation for understanding, support, financial help and hope for a cure.

# Lupus Research Institute Announces Groundbreaking Global Research Initiative

## **\$8 Million Grant Launches Search for Fundamental Causes Driving to a Cure**

NEW YORK, Oct. 17, 2011, /PRNewswire-USNewswire/ -- The Lupus Research Institute (LRI) launched a major international initiative aimed at attracting the highest level scientists to conduct pioneering research to discover the fundamental root causes of lupus, explore the potential for a cure, and transform the field of lupus research. LRI president Margaret Dowd announced the new Distinguished Innovators program amid the nation's foremost scientists gathered at the 11th annual Lupus Research Institute Scientific Conference, "Forum for Discovery."

## **The initiative is being made possible via an \$8 million grant from Bloomberg Philanthropies.**

While current research in the field is developing new treatments to suppress manifestations of lupus, nothing in the drug pipeline addresses root causes or seeks to reverse the disease. Recognizing that the most pivotal advances often come from unexpected directions, LRI is launching the Distinguished Innovator's program to attract the world's best talent and foster cross-disciplinary interactions among immunologists, geneticists, and cell, molecular and systems biologists, with the specific aim of finding the root causes and, from there, developing a cure.

"Lupus is a too often overlooked disease that affects 1.5 million people in this country, and thousands of New Yorkers," said Michael R. Bloomberg, philanthropist and Mayor of New York City. "This grant will fuel the work of the Distinguished Innovators Program and further LRI's demonstrated track record in significantly advancing medical discovery. I am confident this investment will help advance efforts to find both the basic causes of this complex disease and the cure."

## **The Challenge to Change Lupus Research**

LRI is asking the international scientific community — within and beyond those currently working in the lupus space — to build upon the growing knowledge base and advancing technology to launch large-scale innovative projects focused on answering the essential question — What are the fundamental causes of lupus?

"If we can get to the fundamental causes, we can get to the cure," said LRI President Margaret Dowd. "The extremely generous grant from Bloomberg Philanthropies allows us to give the world's leading scientists significant resources and freedom to explore entirely new directions in lupus research over several years. A decade of documented success powered by novel, high-risk, high-reward innovative research has given us the basis to push even further with this bold initiative."

"In science, great achievements are based on a willingness to undertake innovative but risky research, risk based on knowledge, but risk nonetheless," noted world leading immunologist Dr. William Paul, LRI Scientific Advisory Board Chairman and member of the National Academy of Sciences. "The Lupus Research Institute has never shied away from scientific risk-taking. In fact, the Institute has been ahead of the curve in novel lupus research for more than 10 years. Their work has provided the basis for this transformative research initiative to look for the fundamental causes of lupus that can drive to a cure and for the means to prevent lupus."

The LRI Distinguished Innovators Program will begin as a highly competitive, high profile program aiming to award \$1 million grants for transformative large-scale projects that explore uncharted territory to find the primary factors causing lupus with the ultimate goal of attaining prolonged drug-free remission — a cure. The goal is to attract additional major donors to support the program and to build a critical mass of outstanding interactive investigators who are committed to the long-term pursuit of a cure.

## **A Solid Foundation Built on Innovative Science**

Announcing the new program at the LRI annual conference underscores the strong foundation of innovative science already achieved. Presentations included the novel work of more than 35 researchers from many of the country's finest academic institutions such as Yale and Columbia universities, University of Washington, and UCLA. Lupus studies presented covered the role of genes and environment; B cell signaling and regulation; biomarker discovery; targeting T and B cells; harnessing regulatory T cells; and pathways in inflammation.

Of particular note were presentations by Dr. Timothy Niewold (University of Chicago) on newly discovered genetic factors that might help explain why African Americans are more susceptible to lupus; Dr. Jeffrey Rathmell (Duke University) on a new experimental approach to eliminate autoreactive B cells by interfering with their metabolism; and by Dr. Jane Salmon (Hospital for Special Surgery, New York) on an anti-inflammatory pathway triggered by the nervous system that could potentially be harnessed to suppress inflammatory tissue damage in lupus.

The keynote dinner speaker at the Conference was Rockefeller University President Marc Tessier-Lavigne, Ph.D., a world leader in the study of brain development

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and the former chief scientific officer of biotech giant Genentech. An industry forum featuring presenters from EMD Serono, Genentech Cedars-Sinai Medical Center, Harvard Medical School, University of Colorado focused on ways to overcome challenges in translating scientific discovery to therapeutic interventions.

### **About Lupus**

Lupus is a chronic, complex and prevalent autoimmune disease that affects more than 1.5-million Americans. More than 90% of lupus sufferers are women, mostly young women between the ages of 15 to 44. Women of color are especially at risk. In lupus, the immune system, which is designed to protect against infection, creates antibodies that attack the body's own tissues and organs — the kidneys, brain, heart, lungs, blood, skin, and joints. Lupus is difficult to diagnose, difficult to treat, and is a leading cause of premature cardiovascular disease, kidney disease and stroke among young women. While there are no known root causes or cure, the

progress of recent discoveries and treatments in development is encouraging.

### **About the Lupus Research Institute**

The Lupus Research Institute (LRI), the world's leading private supporter of innovative research in lupus, pioneers discovery and champions scientific creativity in the hunt for solutions to this complex and dangerous autoimmune disease. Founded by families and shaped by leading scientists, the LRI mandates sound science and rigorous peer review to uncover and support only the highest ranked novel research to prevent, treat and cure lupus.

With its National Coalition of state and local lupus organizations, the LRI is dedicated to finding new and safer options for treating the disease by improving the design of clinical studies and promoting broad participation in clinical trials.

*SOURCE Lupus Research Institute*

## **Power of One**

### **A Lupus Walk in Memory of Lisa Marie Pineda**

When Lisa Marie Pineda lost her 12 year fight with lupus in May, 2010, she was only 28 years old. Her mother, Patricia Pineda-Ornales was determined to do something positive in Lisa's name. Mother and Daughter had often talked about doing a lupus walk together to raise funds for research and to educate others about the disease. They never had the opportunity to do so.

Patricia knew that a Walk for Lupus was the event she was going to organize in Lisa's memory. She printed flyers and mailed and handed them out. T-shirts and buttons with Lisa's photo were made. Someone donated 100 bracelets with "Because We Remember" for the walkers. On September 18, 2011, over 50 people gathered in Bittersweet Park in Greeley to walk. Before the inaugural walk was over, people were telling Patricia that she needed to do a second walk in 2012. Lisa was open about living with lupus and she never complained. Even with frequent hospital stays – one lasting 66 days, Lisa smiled and continued help others. Patricia says "Lisa had a big heart and she never put a price on anything. She always gave to the fullest."

Patricia is committed to honoring Lisa's giving spirit, her smile and her openness and is already planning ahead for the second annual Lisa Marie Pineda Walk. As Patricia stated: "It is never too late, Lisa touched so many lives, we need to continue."

**You Are Invited To Friend the Lupus  
Foundation of Colorado**



Check out the LFC Page  
Click on Friend  
Meet LFC Friends  
Receive News  
Add Your Voice

**LFC Thanks GSK  
for Program  
Support**

The Lupus Foundation of Colorado wants to acknowledge GlaxoSmithKline for their \$7,500 contribution for lupus education and awareness programs.

# Healthy Living



Dear Gentle People,

Every time I think about stress, I think about the stress that comes from within, the stress that I impose upon myself when I get stressed due to a lupus flare, or due to a symptomatic outbreak such as blood clots or cellulitis, or simply a cold or bronchitis. I feel lousy. Every part of my body has taken a hit and, yes, I AM STRESSED OUT! It takes a while to get over whatever I've got. I get a lot of sympathy because everyone I know has had something like that and can relate on a very personal level.

But you know, the stress that I feel when I am stressed by others is so much more harmful to my wellbeing than the internal stress that I normally get from a day that begins and ends with aches and pains, headache, eyestrain, and other symptoms that together result in a jumble of feeling shaky and miserable – in other words, yucky.

Right now I am dealing with a serious illness that began with blood clots. I was supposed to have back surgery and went to the hospital for my pre-op visit. The doctor checked me over and said that my oxygen level was too low and I needed a CT scan to check on that. The CT scan revealed multiple blood clots, so I was rushed to the emergency room and then to the ICU where I was treated with heparin and Coumadin and stayed a week. Following my return home, I needed oxygen 24/7 and a lot of rest.

Needless to say, the surgery was off the table for the time being. I have to wait at least three months before surgery would even be considered. No treatment except pain management was even to be considered. Three months will be up in mid-November and then the pulmonologist will see me for further evaluation.

My back is killing me. I am allergic to most pain meds. I am using a TENS unit and a back brace and take one pain med twice a day. It's not enough to do the job.

I am stressed by outside factors that have little to do with my internal wellbeing. My husband is very supportive and provides meals, does the laundry, takes me to my doctors' appointments and an occasional movie – whatever I can tolerate. We had to cancel a European trip scheduled for September and hope we can go next Spring. I am not permitted to fly, so I can't visit my children in New York. Life is not the way it was before the blood clots, however it's not life-threatening at this time. I can keep up with my usual activities on a limited basis, but I have had to cut back a great deal on what I usually do and what I like to do.

Stress can be harmful if you let it run your life. Stress can take over your life if you let it, just as anything else can. Remember this: once in a while, life's journey takes you places you don't want to go. But life's journeys can also help you take stock of yourself and lead you to a life full of joy and commitment to doing the things that are really meaningful and fulfilling.

A smile and a hearty handshake (if you can) can go far.

Until next time . . .

Anita

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# Opportunity Called and You Answered

There are so many people living with lupus, caring for someone with lupus, working with someone who is diagnosed with lupus, friends with someone who has lupus – yes you are one of the many.

In 2011, many of you stepped up to help. You volunteered for the **9Health Fairs** to educate and inform the public about this silent, invisible disease called lupus. You represented the Lupus Foundation at many sites for the **Combined Federal Campaign** as part of the designated employee giving program. You represented the Foundation at events organized by **Community Health Charities** for employee-payroll giving.

Some of you witnessed the **Lupus Proclamation Day** at the Capital. Some of you were brave enough to tell your story in this newsletter so others could know they are not alone.

And then there were the two individuals, Penny Leachman and Patricia Ornales who conducted a local **Lupus Walk** as a fund-raising and awareness event in Sterling and Greeley, their respective communities. Penny received positive local media and support from the local business community. Their efforts resulted in funds for the Foundation and laid the groundwork for future events.

A number of you did **Peer-to-Peer** counseling, volunteering to talk with individuals who were newly diagnosed, who were in the midst of a flare and who needed an understanding voice. Your time and compassion made a such a difference in their lives!

Everyone who called the **Lupus Pick-Up** service to donate household discards, books and clothes helped the Foundation. We are reimbursed by the cubic foot and it all adds up to substantial financial help for the daily operations expenses. As individuals, you contributed with checks and credit cards – some through the **Annual Appeal**, some through matching employer contributions, some for memorials and all from the goodness and kindness in your heart.

**You** each had a role in making life better for that person living with lupus. Your help translated to printing and mailing the newsletter, maintaining the web site, offering seminars and education, emergency assistance for those needing financial help and as always for research – so there is a better tomorrow.

Thank you for helping.

Carol Wright  
Chair  
Lupus Foundation of Colorado



## Memorials & Honoraria

### In Memory of Myron and Lorena Andersen

Florence Lipski

### In Memory of Rose Dambeck

Edythe Hittcon

### In Memory of Frank Gioia

Agnes Walsh

### In Memory of Lisa Marie Pineda

Nicole Fagg

Helen Lopez

Billie Martin

Maria Paiz

Trish Pineda-Ornales

### In Memory of Gloria Shelton

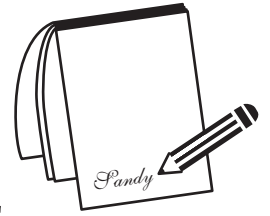
Grace and Bill Baucum

Kay Depice

Aurthur and Joyce Scott

Rickenbaugh Cadillac Company

# Simply Sandy



## Finding Spirit During the Holidays

The winter holidays can present a dichotomy of feelings and situations. One minute we are filled with loving thoughts, positive anticipation, good intentions, and the next, frustration and upset. When our daily agenda is too full of tasks and lacking in spirit, we get off balance and fall into the abyss of despair, sometimes over trivial matters. Are we prone to drama and insanity over a burnt batch of cookies, or can we say “Oh well, in the grand scheme of life, will this really matter in the long run?” What can we do to

ensure a holiday season that is focused on the truly important, even-keeled emotionally, loving and tolerant of others’ quirks and traits, and celebrates the divine gifts and blessings we are privileged to enjoy in our lives? Easier said than done, but definitely worth striving toward:

- Keep it simpler. Expect less and do less than usual. Holidays can be lovely and elegant with good taste and simplicity. Make no comparisons to how your friends and family entertain. Develop your own style with your abilities and limitations in mind.
- Communicate with the people in your holiday circle. Do this early if making changes in old traditions involving guest lists, meals, gifts and activities.
- See change as a positive thing. You don’t have to be a slave to your traditions, especially when they are no longer appropriate. Change can be refreshing, enlightening, and for the better. Embrace the newness of it.
- Ease up on yourself and others. Lowering the bar of expectations for yourself lowers the bar for others as well, and can give everyone some much needed relief from holiday stress.
- Stay focused on spiritual matters, not on appearances and material possessions.
- Keep the fun going. Let go of negative expressions, people, traditions and over-the-top expectations.
- Control your reaction to disappointment, glitches, and accidents. It isn’t the end of the world if a china plate gets broken, a wine glass chipped, or a tablecloth stained. It is easier to replace a glass than replace the lost trust of a loved one when you overreact and make objects more important than feelings.
- Especially control your reaction to those people on your guest list that irritate you. Don’t let them ruin your holiday fun and spirit. Think of them as children who know no better or students in life’s school that haven’t learned “that” lesson yet. Practice being tolerant and non-judgmental of others in your midst.
- Try substituting a service project for gift giving. Everyone can participate in serving at a soup kitchen, collecting for a food bank, donating to a charity, adopting a needy family in the community, cooking a dinner for an elderly or housebound couple, giving a homeless pet a weekend with people, collecting toiletries, blankets, or diapers for a homeless shelter, paying a utility bill for a needy family to keep the heat and lights on, etc.....
- Instead of focusing on just one day, have several group activities. Arrange a cooking or baking session, a tree trimming morning with coffee and donuts, a grocery excursion for filling a charitable food basket, a collection afternoon for coats and warm clothing for the needy, a card-addressing get together, a joint gift wrapping day where everyone contributes materials, a volunteer day on a holiday that is outside your faith.
- Include the children and bring out your “inner child” for more fun and happy memories.
- Delegate by doing potluck meals and asking everyone to contribute to the group activities, work, clean-up.
- Rotate houses where activities take place. This keeps it interesting, fresh and divides the work.
- Keep foremost in mind the reason for the holiday. Celebrate and participate in the spiritual aspects of the holidays and avoid the consumerism that typifies the season.
- Keep spirits uplifted by including stories, inspiring quotes, poems, inspirational writings, music and warmth in your gatherings. Above all, have fun, gratitude, and enjoy this special season.

## To My Family and Friends

- Believe what I say as I don't lie, for
- Appearances can fool even the best observers.
- Don't treat me like an invalid, but please
- Help me when I need it, and not when I don't.
- Be flexible with this unpredictable disease that resembles a roller coaster.
- Hold my hand and walk alongside me, don't abandon me or leave me behind in the dust.
- Talk to me, as silence separates us, builds resentment, and keeps the tension simmering on the stove.
- My health and our lives are more important than the bank balance.
- Give me strokes to help maintain my self esteem and self worth. I feel flawed, like damaged goods.
- I am grieving the loss of my health, career, sports, appearance, productivity, who I was and what I could do. Help me get to acceptance through love and understanding.
- Pain, fatigue, dependence, and disability can make one irritable and depressed. Help me see the bright side of life.
- Don't judge my reactions to my illness. Pray and hope that you are never in my shoes.
- Learn all you can about my illness. Ignorance begets misery and misunderstanding. Knowledge empowers us.
- Let's be compassionate and loving to one another. The illness is burden enough for us all to bear.
- Take me out to the ball game, so I don't withdraw from people and life.
- Recognize my accomplishments, as they required much more effort than usual.
- Let me cry and vent. Just listen. You don't have to fix anything-you can't and I'm not expecting that.
- Leave the guilt trips behind. I feel guilt just for being ill, so please don't add to that pile.
- Don't let me wallow in self pity. Nudge me to keep trudging forward at a pace I can manage.
- Be willing to modify expectations, activities, and daily life. Roles may reverse or change. Adaptability will help us cope and learn through our journey together.
- Let's keep our spirits intact and our higher power in our lives. God may be our best friend, confidant, advisor and doctor.

Sandra Kanowitz, MSN

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### *Drop In - Stop By Open House*

*Thursday, December 1, 2011*

*10:00 a.m. - 3:00 p.m.*

*1211 South Parker Road, Suite 103*

*(Creekside Office Complex)*

*Denver, Colorado 80231*

#### **Why Come?**

- Sign Up for a Support Group
- Provide your thinking on plans for Foundation activities
- Register your thoughts on a new LFC logo
- **Meet Us...We Want to Meet You!**
- Please feel free to share with a friend

**RSVP - 303-597-4050 or [gayna@lupuscolorado.org](mailto:gayna@lupuscolorado.org)**

Lupus Foundation of Colorado, Inc.  
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One of the nation's foremost not-for-profit organizations concerned with Lupus, a network of support and information that reaches your community through immediate, reliable and easy to understand information on:

- living well with Lupus
- preventing complications
- peer support
- short-term counseling & advocacy
- financial assistance
- insurance & employment issues
- comprehensive articles, brochures and videos
- day-to-day Lupus management
- and much, much more

When you have special questions about Lupus, informed answers are just a phone call or email away: Monday through Friday from 8:30 a.m. to 4:30 p.m. (MT) at toll-free 800.858.1292 or [info@lupuscolorado.org](mailto:info@lupuscolorado.org)

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