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Joint Message from the Chairman of the Board and CEO & President

On Sunday, August 9, 2015, Salvatore Lataro, passed away at age of 86.

Sal, as he was known to so many of us, was born and raised in Newark, New Jersey; the youngest of eleven children. Upon graduation from Central High School, in 1948, he went to work for Trans World Airlines (TWA) until his retirement in 1991. As a U.S. Navy Korean War Veteran, Sal served our country on a ship patrolling the waters off of Cuba from 1951-1955. He was married on August 25, 1951, and he and his late wife, Marie, raised their two children, Kathleen and Steven.

As an active member of St. Thomas the Apostle R.C. Church in Bloomfield, New Jersey, Sal served as a Eucharistic Minister and usher. He assisted with the food pantry. He was honored as the Holy Name Society Man of the Year in 2006. He was an honorary member of the Bloomfield Chapter of UNICO and a member of the Bloomfield Council Knights of Columbus.

In 1968, Sal became aware of lupus when his then twelve year old daughter, Kathleen, was diagnosed with the disease. The family would learn more about this unknown disease through the Lupus Foundation of America, New Jersey Chapter, Inc. (LFANJ) and its support group meetings. Sal did everything expected of him but Kathleen suffered from lupus, and specifically lupus nephritis (kidney disease), for many years, until her passing at the age of 42, in 1997.

In 1997, Sal became even more active in the LFANJ. He volunteered his time and his friends. Sal spent each and every day educating people and raising awareness about the disease, fundraising, and advocating on behalf of those affected by lupus.

In 2001, Sal was asked to serve on the LFANJ Board of Directors. In 2009, he was honored at the LFANJ’s Annual Gala Dinner, receiving the Beatrice L. Wesling Service Award for his service and dedication to the Lupus Community. Sal continued to serve on the LFANJ Board until 2014, at which time his health was failing and prevented him from participating.

Sal was one of the finest gentlemen that either of us had ever known. When he passed, several us, including some of our board members and volunteers, and LFANJ founder and past Executive Director, Gloria Spadaro, attended the wake and service. It was no surprise that so many people attended both. Indeed it is a true testament to Sal who has touched so many lives.

Sal was the ambassador for the Foundation. He would come into the office and help with the mailers by stuffing envelopes. He would solicit donations from stores; attend all of our board meetings and committee meetings, and all of our events and programs including the educational meetings, beefsteak dinners, annual walks and gala dinners. Whatever we needed, Sal was there to help.

One time we were applying for a grant for an educational program, and we submitted a voluminous number of documents to apply for this grant. The very next day, Sal walked into the office and gave us a $1,000.00 check, for that program, which he obtained from a local bank. We asked him if they had a grant program and did he fill out paperwork to apply for the grant. Sal said that he went into the bank, told the Vice President that he needed a donation from the bank, and without any paperwork he was given $1,000.00 by the bank. So much for grant applications.
As mentioned earlier, Sal was also an active member of UNICO (an Italian American Service Organization). Over the past several years, he and Lenny would attend an annual UNICO dinner in Scotch Plains to accept a donation, on behalf of the LFANJ, from that UNICO chapter.

One year, thirteen advocates, representing the State of New Jersey, drove to the Washington, DC for Lupus Advocacy Day. There was Sal with twelve women. Ranit was one of those twelve and I remember how passionate he was when speaking with our senators, congressmen and their health aides; all on behalf of lupus patients everywhere. He carried a picture of Kathleen, his daughter, and showed that photo to everyone, while reminding them of how tragic lupus can be. His passion and devotion was never-ending. After an exhausting day on the Hill we had gone out to dinner as group. Sal held the door for each of us. He then pulled out a chair as each of us sat down for dinner. He was simply a true gentleman in every sense of the word, and he carried his heart on his sleeve.

Sal’s love of people was remarkable and his fight to cure lupus was inspiring. He knew every board member’s story and their relationship to lupus. He never forgot a birthday and would always take time to send a card, or two each year. He was truly a special human being and for that reason we have chosen to establish the Salvatore Lataro Humanitarian Award, in honor of Sal’s memory. This award will be given at our annual meeting to a worthy recipient.

Even though Sal is no longer with us, he has set the bar as high as it will go. He has lead by example. He has demonstrated selflessness and altruism throughout his life. He will be greatly missed by all who knew him.

Lenny’s father used to say that it was not strictly true that you came into this world with nothing and leave with nothing. His father use to say that you came into this world with nothing but you leave with your character. This truly applies to Sal Lataro. He touched everyone he met.

Sal, may you rest in peace. Steven and Ginny, our condolences to you and your loved ones.

--Ranit Shriky, Chairman and Lenny Andriuzzi, President and CEO

AmazonSmile is a simple and automatic way for you to support your favorite charitable organization every time you shop, at no cost to you. When you shop at smile.amazon.com, you’ll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added bonus that Amazon will donate a portion of the purchase price to your favorite charitable organization. You can choose from nearly one million organizations to support, including the Lupus Foundation of America, New Jersey Chapter, Inc. To shop at AmazonSmile simply go to smile.amazon.com from the web browser on your computer or mobile device. On your first visit to AmazonSmile, you need to select a charitable organization to receive donations from eligible purchases before you begin shopping. We will remember your selection, and then every eligible purchase you make will result in a donation.

Walk To End Lupus Now™

Our walk event, takes place on October 11, 2015 at Nomahegan Park in Cranford, New Jersey. Check-in and registration start at 9:00 am, and the Walk steps off at 10:00 am. There is still time for you to register online at www.lupusnj.org or by using the form in this mailing. Please remember to ask your donors to find out if they can double their donation by asking about workplace giving. Many corporations have a matching gifts program. For more information please contact the LFANJ at 973-379-3226.

Membership Renewal

Now is the time to renew your membership with the Lupus Foundation of America, New Jersey Chapter, Inc. (LFANJ). If you were a member and have let your membership lapse, consider renewing. Being a member means that you will receive our quarterly newsletter, an update on the latest in lupus research and educational programs, the national Lupus Now® magazine, and information on our upcoming educational seminars and fundraisers.

Your membership dues help us to provide the services to the people affected by lupus and their families. Thank you for taking the time to renew your membership!

Helpful Websites and Resources

- www.lupusnj.org
- National Institutes of Health: Health News & events (http://www.nih.gov/news/)
- www.lupus.org
As science moves further in its quest to understand and treat systemic lupus erythematosus (SLE), more and more scientists are looking to find treatments for lupus nephritis as well. Lupus nephritis, which may affect about 40% of lupus patients, involves inflammation of the kidneys and can, in some cases, result in patients requiring dialysis or a kidney transplant. Thankfully, doctors and scientists across the globe are working to find new, effective ways of managing the disease to prevent it from progressing to later stages.

Clinical research sites are currently working on several different clinical trials for those with lupus nephritis. Below are descriptions of three clinical trials that are currently open for recruitment.

**HGS1006-C1121: A Phase 3, Randomized, Double-Blind, Placebo-Controlled Study to Evaluate the Efficacy and Safety of Belimumab plus Standard of Care versus Placebo plus Standard of Care in Adult Subjects with Active Lupus Nephritis**

The first study explores whether Benlysta (belimumab) can be an effective treatment for lupus nephritis. Benlysta was approved for lupus patients in 2011; however, the earlier studies for the drug did not include patients with lupus nephritis. This new study looks to see if Benlysta can help lupus nephritis patients as much as it is able to help SLE patients. Key inclusion criteria include having a positive ANA titer, a protein/creatinine ratio > 1, and the presence of urinary sediment (i.e., red blood cells). Subjects will be started on either Cell Cept (mycophenolate mofetil) or Cytoxan (Cyclophosphamide) within 60 days before the start of the study, and cannot join the study if they have used other B-cell targeted treatments (such as Rituximab) or another investigational agent within the past year.

**ITN055AI: Rituximab Plus Cyclophosphamide Followed by Belimumab for the Treatment of Lupus Nephritis**

The next study also explores the efficacy of Benlysta for lupus nephritis patients. However, this study pairs the drug with Rituxan (rituximab) and Cytoxan. Patients are randomly assigned to one of two groups. One group receives Cytoxan and rituximab, and then undergoes a steroid taper. A second group also receives Cytoxan and rituximab, but then receives monthly Benlysta infusions for a year while their steroids are tapered. Key inclusion criteria include having a positive dsDNA test, a protein/creatinine ratio >1, and sediment in the urine if a kidney biopsy is older than three months. Patients must have already tried either mycophenolate mofetil or cyclophosphamide, and cannot have ever been treated with a biologic B-cell therapy (such as Benlysta or rituximab).

**AURA-LV: Aurinia Urinary protein Reduction Active – Lupus with Voclosporin**

The third study involves a new drug called Voclosporin. Voclosporin has a very similar chemical make-up to the drug cyclosporine, which is already used to treat lupus nephritis. However, in earlier tests Voclosporin was shown to bind 3 – 5 times more tightly than cyclosporine, leading investigators to believe that it may be a more effective treatment for lupus nephritis. Voclosporin is taken twice a day orally and will be administered along with mycophenolate mofetil while tapering steroids. Key inclusion criteria include a protein/creatinine ratio of either ≥ 2 or ≥ 2.5 depending on your class of lupus nephritis. Patients cannot have taken cyclosporine within a year or biologics within three months, and if patients are currently taking azathioprine, they will be switched to mycophenolate mofetil at the randomization visit.

If you are a patient with lupus nephritis and believe you would be a good candidate for any of these studies, please contact a clinical research investigative site near you. Participating centers are listed on clinicaltrials.gov. Centers participating specifically in studies on lupus nephritis can be found at the following web site link: https://clinicaltrials.gov/ct2/results?term=lupus+nephritis&Search=Search.

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**“Do not sit back. LEAN FORWARD and GET INVOLVED. You are not alone.” - Leonard Andriuzzi, President & CEO**

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**Artist for the Night at the Paintbrush Studio in Maywood, New Jersey**

Join us for an evening of BUTTERFLY PAINTING for Lupus at the Paint Brush Studio in Maywood, New Jersey. This amazing fundraising event will be held on Saturday evening, September 12th, from 7:00 pm until 10:00 pm. Tickets are $45.00 per person and include painting supplies, desserts and beverages. There will be a 50/50 raffle and a door prize: an Apple Mini iPad. Please join us for what is sure to be a spectacular evening of fun. For more information, please go to http://www.lupusnj.org/newjersey/events/entry/nj-artist-for-the-night. To register go to http://www.paintbrushstudio.com/. Thank you for making a difference in the lives of those affected by lupus.

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**Help Raise Funds with the LFAQJ Shopping Mall Partners**

It is very simple. Go onto our website, www.lupusnj.org, and click on our Donate button, select The New Jersey Chapter, Inc. Shopping Mall link or click on the rotating ad on the homepage for the shopping mall. Click on the logo for the store you wish to visit and follow the prompts. The key is to enter the store's web site by first going through our web site. If you go directly to their website, the LFANJ will not get credit. By shopping online, and using the LFANJ website, you will be purchasing the goods and services that you want, and you will also be helping to support the LFANJ and our lupus community. Every time you shop, you will making a difference. So start shopping!
Holiday Raffle

We will soon be sending out our Holiday Raffles. There are only 200 tickets at $50.00 per ticket. It is a 50-50 raffle. If we sell all 200 tickets the winner will receive $5,000.00. If we do not sell all of the tickets the winner will receive 50% of the amount collected. These odds are better than the lottery. For more information or to purchase the raffle tickets, please call 973-379-3226.

Our Mission...

to educate and support those affected by lupus and to find a cure.

The LFANJ would like to thank all of the above sponsors and volunteers who supported this event. Thank you for making a difference in the lives of those affected by lupus.

The Foundation would like to thank our former liaison to the Somerset Patriots, Brian Cahill. Brian has been a true friend to the LFANJ. We wish him well and much success in his future endeavors.
Ask the Doctor  
According to lupus specialists, it is important that patients prepare for their doctors appointments by asking a few questions regarding their current health condition. Going to your doctor to have lupus treated can be a stressful. Limit your stress by having a few prepared questions to ask before your visit.

- What do I want to ask the doctor today?
- The symptoms that bother me the most are What, Where and When did they start? Do they change over time? How long do they last? NOTE: Bring copies of any completed self-monitoring forms/diaries.
- What medications (prescriptions, over-the-counter, supplements and vitamins am I taking regularly? (List name(s) and dosage below or bring the bottles with you.)
- What are my goals for treatment and what do I want or expect to get out of treatment?
- Is there anything that concerns me about my health or treatment (e.g. effect of lupus on work, family, mood; problems following recommended treatment plan)? □yes or □no

LUPUS Now Magazine: Questions and Answers Fall 2011
Reviewed by Jason Konig Health Educator/Case Manager
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Support Group News:  
Come join one of our support group meetings, learn about lupus and address your concerns. Connect with others who have lupus and make new friends. The support group meetings flyer is available as a separate flyer in this edition of the Lupus Link. It can also be located on our website: www.lupusnj.org.

Ongoing Support Group Recruitment:  
We are currently seeking support group facilitators in the following counties: Hudson, Hunterdon, Somerset and Ocean. In addition, we are in need of volunteers willing to help with occasional health fairs on weekdays and Saturdays.

Check out the updated Support Group Meetings Flyer in this issue of the Lupus Link!

Teen Corner: Helping Teenagers Understand Lupus

Since you were diagnosed with lupus, you probably wonder if you are still going to be able to go on those yearly family vacations, go to camp or go away to college. Having lupus does not mean that you have to leave behind your future plans and dreams. It might just mean that you have to be more careful when it comes to making certain decisions. If you plan on going away to college, let your doctor know so that he or she can help you prepare. Your lifestyle might have to change after developing lupus. You may not be able to stay up late and watch your favorite shows because you need your rest. You might have to lighten your work load to give your mind and body time to rest and relax.

Reviewed by Jason Konig Health Educator/Case Manager
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For Inquiring Teens With Lupus; Our Thoughts Issues & Concerns
Hospital For Special Surgery ● www.hss.edu

WHAT IS LUPUS?

Lupus is an autoimmune disease. Think of your body’s immune system like an army with hundreds of soldiers. The immune system’s job is to fight foreign substances in the body, like germs and viruses. But in autoimmune diseases, the immune system is out of control. It not only attacks germs, but healthy tissue as well.

You can’t catch lupus from another person. It isn’t cancer, and it isn’t related to AIDS.

Lupus is a disease that can affect many parts of the body. Everyone reacts differently. One person with lupus may have swollen knees and fever. Another person may be tired all the time or have kidney trouble. Someone else may have rashes that come and go. Lupus can involve the joints, the skin, the kidneys, the lungs, the heart, the brain, and the nervous system. If you have lupus, it may affect two or three parts of your body. Usually, one patient doesn’t experience all the possible symptoms. Lupus can vary from mild to severe, and usually alternates between periods of activity and periods when the disease is mostly quiet.

Most importantly, lupus is a manageable disease. With proper diagnosis and treatment, the disease is now more manageable than in years past. People with lupus are living full and productive lives. So if you suspect you may have or be at risk for lupus, take action and see your doctor right away. That’s the only way to help manage it. Studies have shown that patients who are informed and involved in their own care:

- Have less pain
- Make fewer visits to the doctor
- Feel better about themselves
- Remain more active

DID YOU KNOW:

- Lupus is 6-10 times more likely to be found in women than in men?
- Lupus affects women of color (African Americans, Hispanic Americans/Latinas, Asian Americans, and Native Americans) 2-3 times more often than women of European descent?
- Although lupus can affect men and women, more than 90 percent of people with lupus are women between the ages of 15 and 45?
- Both African Americans and Hispanic Americans/Latinas tend to develop lupus at a younger age and have more symptoms at diagnosis (including kidney problems)?
- African American lupus patients have more seizures and strokes, while Hispanic American/Latina patients have more heart problems? (We don’t understand why some people seem to have more problems with lupus than others.)
Heart disease, cancer, Alzheimer’s disease, the metabolic syndrome, physical disability. That’s just a partial list of the illnesses that have been linked to chronic inflammation.

“It’s different from the classic, red, swelling, white-cell kind of inflammation that we’re used to thinking of,” explains Walter Willett, chair of the Nutrition Department at the Harvard School of Public Health.

Instead, it’s more of a slow burn that’s detected only by a rise in inflammatory signals, or markers—proteins produced by the immune system to fight infection or heal an injury (though not the kind of injury you can necessarily see or feel). The question is: how can you douse the flames? So far, only one thing is clear, says Willett. “The most powerful way to reduce your inflammatory factors is to lose excess weight.”

Omega-3 vs. Omega-6 Fats
Why would omega-3 fats—like the EPA and DHA in fish oil or the ALA in flaxseed—quiet inflammation?

“It goes back to the idea that the omega-6 fatty acids produce eicosanoids that have pro-inflammatory effects,” explains William Harris of the University of South Dakota Sanford School of Medicine. (Corn, soybean, and sunflower oils are rich in omega-6.)

“The omega-3 fats produce their own version of those eicosanoids, which are kinder and gentler,” he adds.

That’s how omega-3s got their anti-inflammatory reputation. “And it’s been seen in some rheumatoid arthritis trials, where inflammation is rampant and “where relatively high doses of omega-3s reduce sore joints,” says Harris.

At first, the evidence that omega-3s could also quell inflammation in people with lower levels of inflammation seemed promising.

“Studies found that people with higher omega-3 intakes had lower inflammatory marker levels,” says Harris. But when researchers gave omega-3s to people with or without heart disease, inflammation didn’t budge.

“In the majority of studies where they’ve given fish oil to people in a randomized trial, it didn’t lower inflammatory markers,” acknowledges Harris, who is also president and CEO of a company that measures omega-3 levels in red blood cells. “There are counter examples, but that’s the usual experience.”

It’s not clear why. “It could take years of a high intake to change the markers,” Harris suggests. “Or it could be that people who eat more fish are more careful about other lifestyle factors,” and that’s why they have less inflammation.

Another possibility: maybe the studies aren’t measuring the right thing.

“If you get exposed to bacteria or a virus, you want an inflammatory response because it helps with healing and fighting the infection,” says Penn State’s Penny Kris-Etherton. “It’s only when the inflammation smolders for a long time that it wreaks havoc.”

So she’s launching a new study to test the body’s response to infection. “We’re giving people EPA and DHA”—the omega-3s in fish oil—“at different doses over a long period of time and then injecting them with E. coli bacteria at a very, very low dose,” she explains.

The question: “If you supersaturate your cells and membranes with omega-3 fatty acids, will that not only quell an inflammatory response, but also quench a resolution?”

Fish oil may protect the heart whether or not inflammation plays a role. In one Italian trial, fish oil lowered the risk of a second heart attack. And in a Japanese trial on 18,000 people who were taking cholesterol-lowering statin drugs, EPA helped those who had high triglycerides and low HDL ("good") cholesterol. “They had a 50 percent drop in risk of cardiac events,” notes Harris.

In view of those trials and other evidence, the American Heart Association recommends that everyone eat fatty fish at least twice a week.

Other Foods
■ Mediterranean diet. Italian researchers assigned 180 people with the metabolic syndrome to eat either a Mediterranean diet (rich in fruits, vegetables, whole grains, beans, and olive oil and low in saturated fat) or to follow advice on “healthy food choices.”

After two years, the Mediterranean group had lower levels of several inflammatory markers, but that may be because they also lost more weight.

■ Olive oil & nuts. In a Spanish study of roughly 100 people at risk for cardiovascular disease, inflammatory markers dropped more in those assigned to eat a Mediterranean diet with extra olive oil or nuts than in those who ate the same diet without extra olive oil or nuts. But results from other studies differ.

■ Whole grains. In three studies, inflammatory markers were no lower in people assigned to eat whole grains than in those who got refined grains.

■ Fruits & vegetables. In a German study, men who were told to eat 8 servings of fruits and vegetables a day had lower levels of the inflammatory marker C-reactive protein (CRP) than those told to eat 2 servings a day, but the difference was partly due to a rise in CRP in the 2-serving group. Another study found no change in CRP when overweight postmenopausal women were told to eat 2, 5, or 10 servings of vegetables a day.

■ Legumes. In a Spanish study of 30 obese men and women, those told to cut calories and eat four servings (each about a cup) of lentils, chickpeas, peas, or beans a week had lower CRP levels than those who cut calories without eating legumes. (The bean eaters lost more weight, but the researchers adjusted for that.) But none of that is enough evidence to be sure that beans—or any foods—matter. The bottom line: replacing meats, sweets, and refined grains with beans, fruits, vegetables, whole grains, and fish—and substituting oils for butter and margarine—is smart, even if it doesn’t change your inflammatory markers one iota.

The Bottom Line
1. Inflammation has been linked to heart disease, cancer, metabolic syndrome, Alzheimer’s disease, and muscle loss with aging. But the evidence is inconclusive that lowering inflammation prevents those diseases.

2. Losing excess weight is the best way to curb inflammation.

3. Exercise can reduce inflammation if it helps you lose weight or if you have high levels of inflammation, which are common among older people.

4. It’s wise to eat a diet rich in seafood, beans, vegetables, fruit, and whole grains and to replace butter and margarine with oils. However, it’s too early to know if those changes can curb inflammation.