LUPUS LINK

Message from the President & CEO

Summer is slowly fading in the rear view mirror, and before we know it visions of turkey and stuffing will come into view. We hope you had a restful and fun summer.

During the summer, we start planning our fall and winter programs and events. We are starting our new fiscal year with the Montclair University Walk, which was postponed due to bad weather. The walk will held in either late September or early October. The date has not been fixed as of yet. We are also getting ready for our annual Walk to End Lupus NowTM which will be held on Sunday, October 23, 2016 at Nomahegan Park in Cranford, New Jersey.

Lupus Awareness Night, with the New Jersey Devils versus the Nashville Predators, will be held at the Prudential Center in Newark, New Jersey on Tuesday, December 20, 2016.

Our first educational seminar of the year will be held in New York. We are co-sponsoring an educational seminar with the Lupus Foundation of America, Northeast Region and NYU Langone Medical Center. The seminar will be held on Saturday, October 29, 2016 at the NYU Langone Hospital for Joint Diseases in New York, New York.

We are also in the process of setting up the schedule for the support group meetings. This year we have added Morris County. Dates and times for the support group meetings are available on our website at lupusnj.org/ (http://www.lupus.org/newjersey/pages/support-groups).

On the advocacy front, the LFANJ has been active, along with other groups, in advocating for the people affected by lupus, and are part of two coalitions. One is attempting to have legislation passed to lower the costs of medications and the other is to place more stringent controls on non-medical switching of medications by the insurance companies.

As we have explained in the past, the LFANJ is indeed a not-for-profit entity, but in reality we are no different than a small business, except that we are not in business to make a profit. We pay for rent, utilities, salaries, supplies, telephone services, internet services, printing services, venues, etc. Most small businesses pay for these items by selling a product and making a profit from the sales of the product. We do not have this luxury. Our only source of income is through fundraising, and in these difficult economic times, it has been a challenge. We receive no federal or state funding. We know people are financially strapped and many live paycheck to paycheck. In order for us to provide the services you want and need, we have to raise funds. In the past year, we put together three educational seminars, which are not fundraisers, but still have cost us. We held a Beefsteak Dinner, which was a very popular fundraiser in past years. This year, we lost money on this event and as a result we have decided to no longer hold this event. We held a Lupus Awareness Night at the Somerset Patriots’ TD Ballpark and again lost money on this fundraiser.

Over the past few years, fewer and fewer people are coming to the events or are participating in our educational seminars. We want to assist as many people as possible in the fight against this terrible disease, but we cannot do it without your support. We need, not only, financial support but also volunteers who can donate their time to the LFANJ. Our annual Walk To End Lupus NowTM in October is our biggest fundraiser, but produces less and less revenue each year. We started our walks many years ago, and maybe had two or three hundred people attend, and the walks were very successful. In the past three years we have had over twelve hundred people participate at each walk at Nomahegan Park in Cranford, and only about two hundred who actually made or brought in donations.

We are currently running a calendar raffle that will end in September and will be running our 50-50 Holiday Raffle in the fall. Please consider donating, by taking more than one raffle ticket, attending our functions and financially supporting the LFANJ, so that we can continue to fulfill our mission which is dedicated to improving the quality of life for those affected by lupus through research, education, and advocacy.

Thank you for making a difference in the lives of those affected by lupus.

Leonard J. Andriuzzi, Esq. President and CEO and Ranit C. Shriky, Chairman
9 Signs Of Lupus All Women Should Be Able To Recognize

The autoimmune disease can have countless impacts on the body. Here are the most telltale symptoms.

Like many autoimmune diseases, lupus affects more women than men. In fact, 90 percent of people diagnosed with the life-long condition are young women between the ages of 15 and 34, according to the S.L.E. Lupus Foundation. (S.L.E. stands for systemic lupus erythematosus, the full name of the disease.)

As with its chronic cousins Hashimoto’s thyroiditis, multiple sclerosis, and more, there’s no known cause. Experts suggest a mixture of genetics and environment, but it’s still a mystery as to why some develop lupus. It’s also very hard to diagnose because the effects are broad-ranging and often look like any number of other conditions.

“Lupus can affect almost any part of the body. In a sense, that makes it quite unique to all human diseases,” Jill Buyon, M.D., director of the Lupus Center at NYU Langone Medical Center, tells SELF. Its symptoms also vary immensely from person to person. “The main message is that my lupus may be different from your lupus,” Buyon says. “We could have 333 people in a room and none of them have the same presentation until the 334th person walks in,” she explains. Some people get hit hard with symptoms right away, while others may experience one or two subtly that worsen over time. Unspecific symptoms, such as fever and lymph node swelling, can occur because of lupus, but fail to signal the disease to doctors in the absence of other telltale signs. A diagnosis usually takes a “constellation of signs and symptoms,” says Buyon.

While generally feeling unwell or like something is “off” is common among those who are ultimately diagnosed with lupus, the specific signs and symptoms of the disease are plentiful. “There are dominant features,” Buyon notes—symptoms that are very characteristic of the disease and can help doctors recognize what’s going on. Below are the most common signs of lupus. If you think you may have it, see your doctor to talk about your concerns ASAP.

1. Joint swelling and pain

“Joint pains and joint swelling and stiffness in the morning,” are all classic signs of lupus, Buyon says. It most commonly presents in the wrists, knuckles, and fingers. This also makes it easy to confused with rheumatoid arthritis. “The textbook difference between lupus and rheumatoid arthritis is that lupus can affect joints on one side and not the other, whereas RA usually affects both sides equally,” Buyon explains. Swelling can also come and go with lupus and doesn’t get progressively worse and disfiguring like it does in RA. “Lupus also tends to occur in younger patients.”

2. Face rash

Developing a skin rash when exposed to sunlight is a very characteristic symptom of lupus. It’s called a butterfly rash and usually extends from the bridge of the nose, down the cheekbone, to the jawbone.

3. Water retention and bloody urine

Kidney problems are another hallmark symptom and typically occur in more serious manifestations of the disease. The problem is, that someone can have deteriorating kidneys without knowing until it gets bad, Buyon says. Kidney problems can cause water retention, resulting a swollen or puffy feeling, and causing water-weight gain. It can also lead to bloody urine.

Membership Renewal

Now is the time to renew your membership with the 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!
4. Chest pain

Lupus often causes inflammation of the heart or its outer or inner linings. This results in shortness of breath, sharp chest pain, interrupted blood flow, and ultimately an increased risk for heart disease. Lupus can also affect both the inside of the lungs and the outside lining. “Some people say it hurts when they take a deep breath—that’s fluid around the lungs.” If your chest is bothering you when you breathe, that’s a red flag.

5. Fatigue

It’s a big symptom of lupus, but unfortunately, it can also represent a lot of different diseases. Lupus can cause blood problems like anemia, which result in low energy levels, and this overall feeling of exhaustion can come from any of the many things going on inside your body—having unhealthy kidneys or lungs or a heart can leave you exhausted.

6. Hair loss

“It’s often in the frontal region, and sometimes can cause embarrassing baldness” because of how drastic it is, Buyon says. It can also cause sores in the scalp. If you present with this symptom, you should also have your thyroid evaluated, Buyon says. Hair loss is a classic symptom of hypothyroidism.

7. Mouth sores

Unlike a typical canker sore or abscess, these sores are usually painless, so many patients may not even know they have them, Buyon notes. They typically present on the roof of the mouth, and sometimes in the nose.

8. Seizures and memory loss

Lupus can also attack the brain. “It can affect the brain, no question, you can have seizures, disorientation, become psychotic, and experience memory loss,” Buyon says. While a lot of patients’ brains are impacted by the disease, others don’t experience these symptoms at all.

9. Mental health problems

“I also think anxiety plays a big role because unlike any other sickness (besides IBD), you can be well today and sick and hospitalized tomorrow. That’s a scary thought. The unpredictable nature of one’s health can be very anxiety provoking.” Feeling unstable and also not knowing what’s wrong makes matters even worse. Living with fear and anxiety about your health is par for the course with lupus, and even without other symptoms, is a sign enough that you need to talk to someone to figure out what’s going on.

SELF – August 7, 2016
Nine Signs of Lupus All Women Should Be Able to Recognize – By Amy Marturana
Jill Buyon, MD, Department of Medicine, Division of Rheumatology, Lupus Center
Resources Available for the Lupus Community

**Partnership For Prescription Assistance** helps qualifying patients who lack prescription coverage get the medication they need through the public or private program for free or at a savings ([www.PfizerRXPathways.com](http://www.PfizerRXPathways.com))

**Pharmaceutical Assistance to the Aged & Disabled (PAAD)** The Pharmaceutical Assistance to the Aged and Disabled (PAAD) program, the Lifeline program, and the Hearing Aid Assistance to the Aged and Disabled (HAAAD) program are three State programs with similar eligibility guidelines. ([www.state.nj.us/humanservices/doas/services/paad/](http://www.state.nj.us/humanservices/doas/services/paad/))

**Catholic Charities** provides non-denominational emergency assistance, food, clothing, shelter, and counseling services to those in need ([catholiccharitiesusa.org](http://catholiccharitiesusa.org))

Help Raise Funds with the LFANJ Shopping Mall Partners

It is very simple. Go onto our website, [http://www.lupusnj.org](http://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. Then, 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!**

### Why Donate?
- Donations are tax deductible
- Giving to charity may improve your sense of well-being
- Giving to charity out of spiritual conviction can strengthen your spiritual life
- Volunteering with a charity may result in physical and social benefits
- Set an example
- Be part of something bigger
- Giving to charity is an opportunity to give something back
- Charity reflects on your own inner values
- Because you can make a difference in the lives of those affected by Lupus

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](http://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. (LFANJ).**

To shop at AmazonSmile simply go to [smile.amazon.com](http://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.

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**Know Your Benefits**

by Amy Paturel, M.S., M.P.H., *Lupus Now ® Fall 2013*

Reviewed by Jason Konig

If you’re among the 15 percent of Americans who are uninsured, getting some type of coverage is the first step. Medicaid is an option for some people, but limitations vary from state to state, and coverage is often restricted to children and people with children. Health discount cards offer another alternative. The cards aren’t insurance, but they do offer lower prices at pharmacies, hospitals, and clinics.

If you have health insurance, select a plan that offers the greatest bang for your buck. Are you always visiting specialists? Choose a policy that features low co-pays, even if you have to pay steeper premiums. “People with lupus are on medication and they may have multiple doctor visits at any given point, so a lower-deductible, higher-premium plan may be in their best interest,” says Carla McSpadden, R.Ph., C.G.P., director of professional affairs for the American Society of Consultant Pharmacists.

Once you have a plan, take stock of the physicians, facilities, and providers in your insurance’s network—and stick with them. And when your in-network physician refers you to a specialist, make sure that provider is in your network, too. “Staying in-network can save you hundreds, even thousands, of dollars a year,” says Christie Hudson, vice president of Medical Billing Advocates of America. Because insurers use their muscle to negotiate discounted rates with in-network providers, out-of-network providers can charge as much as 50 percent more for their services. And don’t forget that you’re on the hook for the portion of the bill that exceeds what your carrier considers an appropriate fee, Hudson says. “When you go out of network, you’re not protected from unreasonable and customary charges,” she says, meaning facilities can bill basically whatever they want.

Even in-network prices can vary by as much as 500 percent, so do your research. You can start by visiting the [U.S. Department of Health and Human Services Web site](https://www.hrsa.gov/) to find cost comparisons for hospitals and medical facilities across the country, as well as detailed information on what Medicare pays for common procedures. “This is a helpful guide even if you’re not on Medicare,” says Hudson. “Just expect to pay about 25 percent more than the Medicare allowance.”
LIVING WELL WITH LUPUS  Reviewed by Jason Konig Health Educator Case Manager

Why Is Exercise So Important in Managing lupus, and What Exercises Could I Do With lupus?

July 2016, LFA, Inc. lupus.org website

Whether or not a person has lupus, exercise is an important way to take care of yourself. Exercise has many physical, emotional and social benefits. It is particularly helpful for people with lupus for many reasons, and most people with lupus can take part in some form of activity.

From a physical standpoint, exercise can strengthen parts of your body that may be affected by lupus — the heart, lungs, bones and joints. It can help reduce inflammation by regulating some of the chemicals involved in the inflammation process. Exercise can help control weight gain caused by use of corticosteroid medications and keep your body conditioned. It can also reduce fatigue. Regular exercise and even simple low-impact movement will make muscles less stiff, increase your range of motion and help you reduce the risk of heart disease.

Exercise may also boost your mental health, making it easier to cope with life stressors and potentially improving mood and self-esteem. Exercising with a buddy can give you the moral support to stick with your exercise routine while making your fitness time double as social time.

Be sure to discuss your exercise plans with your physician or exercise specialist in order to maximize results and minimize possible harm. Activities such as walking, swimming, bicycling, low-impact aerobics, certain types of yoga, Pilates, stretching, water exercise or using an elliptical exercise machine will strengthen your bones and tone your muscles without aggravating inflamed joints. At the same time, these activities help to lower the risk for developing osteoporosis. It’s also a good idea to vary the exercises, so that different muscle groups all get a regular workout.

If you are experiencing swollen joints or muscle pain, you should avoid or at least limit activities that may be demanding on joints and muscles, such as jogging, weightlifting, or high-impact aerobics. If you find that you tire easily when you exercise, you should pace yourself. The most important thing to remember is to not give up exercising, as muscles that are not used will quickly become weak.

With Gratitude....

We would like to thank Jason Konig for his time with the LFANJ. Jason spent the past six years helping many individuals who are affected by lupus. He took time to speak with and listen to patients and family members. He provided referrals and information on various topics. Jason attended health fairs and offered additional resources to our support group facilitators and meeting attendees. Jason left the LFANJ in August 2016 to work with the New York State Department of Health. In his new role he will help families understand the importance of inoculations for their children. On behalf of the Board of Directors, Staff, Support Group Facilitators, and Volunteers, we wish Jason all the best and much success.

Support Group News  Come join one of our support group meetings, and learn about lupus and address your concerns. Connect with others who have lupus and make new friends. The support group meeting listing 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 leaders in the following counties: Bergen, Hunterdon, Ocean and Somerset. In addition, we are need of volunteers who would like to help with occasional health fairs on Saturdays. Bergen County Support Group is currently canceled. Please contact the LFANJ if you would be interested in facilitating this group.

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

Helpful Websites and Resources on Lupus, Physician Referrals and Clinical Trials

www.ClinicalTrials.gov
www.dxlupus.org
www.HealthGrades.com
www.lupusnj.org
www.RA.com
www.Rheumatology.org
www.TheLupusInitiative.org

Organize an Event or Activity  If you are interest in organizing an event or activity on behalf of the Lupus Foundation of America, New Jersey Chapter, Inc. please advise the office of your interest in supporting the Foundation. We can provide information on lupus and help make your event or activity fun and educational. To find out more information please visit our website at www.lupusnj.org or call the office at 973-379-3226. Thank your for your interest and support of the LFANJ.
choose MyPlate

10 tips to a great plate

Making food choices for a healthy lifestyle can be as simple as using these 10 Tips. Use the ideas in this list to balance your calories, to choose foods to eat more often, and to cut back on foods to eat less often.

1 balance calories
Find out how many calories YOU need for a day as a first step in managing your weight. Go to www.choosemyplate.gov to find your calorie level. Being physically active also helps you balance calories.

2 enjoy your food, but eat less
Take the time to fully enjoy your food as you eat it. Eating too fast or when your attention is elsewhere may lead to eating too many calories. Pay attention to hunger and fullness cues before, during, and after meals. Use them to recognize when to eat and when you've had enough.

3 avoid oversized portions
Use a smaller plate, bowl, and glass. Portion out foods before you eat. When eating out, choose a smaller size option, share a dish, or take home part of your meal.

4 foods to eat more often
Eat more vegetables, fruits, whole grains, and fat-free or 1% milk and dairy products. These foods have the nutrients you need for health—including potassium, calcium, vitamin D, and fiber. Make them the basis for meals and snacks.

5 make half your plate fruits and vegetables
Choose red, orange, and dark-green vegetables like tomatoes, sweet potatoes, and broccoli, along with other vegetables for your meals. Add fruit to meals as part of main or side dishes or as dessert.

6 switch to fat-free or low-fat (1%) milk
They have the same amount of calcium and other essential nutrients as whole milk, but fewer calories and less saturated fat.

7 make half your grains whole grains
To eat more whole grains, substitute a whole-grain product for a refined product—such as eating whole-wheat bread instead of white bread or brown rice instead of white rice.

8 foods to eat less often
Cut back on foods high in solid fats, added sugars, and salt. They include cakes, cookies, ice cream, candies, sweetened drinks, pizza, and fatty meats like ribs, sausages, bacon, and hot dogs. Use these foods as occasional treats, not everyday foods.

9 compare sodium in foods
Use the Nutrition Facts label to choose lower sodium versions of foods like soup, bread, and frozen meals. Select canned foods labeled “low sodium,” “reduced sodium,” or “no salt added.”

10 drink water instead of sugary drinks
Cut calories by drinking water or unsweetened beverages. Soda, energy drinks, and sports drinks are a major source of added sugar, and calories, in American diets.

Go to www.choosemyplate.gov for more information.
be active adults

10 tips to help adults include physical activity into their lifestyle

1. Start activities slowly and build up over time
   If you are just starting physical activity, build up slowly. This will help to prevent injury. After a few weeks, increase how often and how long you are active.

2. Get your heart pumping
   For health benefits, do at least 2½ hours each week of physical activity that requires moderate effort. A few examples include brisk walking, biking, swimming, and skating. Spread activities over the week, but do them at least 10 minutes at a time.

3. Strength-train for healthy muscles and bones
   Do strengthening activities twice a week. Activities that build strength include lifting weights, doing push-ups and sit-ups, working with resistance bands, or heavy gardening.

4. Make active choices throughout the day
   Every little bit of activity can add up and doing something is better than nothing. Take the stairs instead of the elevator, go for a 10-minute walk on your lunch break, or park farther away from work and walk.

5. Be active your way
   Mix it up—there are endless ways to be active. They include walking, biking, dancing, martial arts, gardening, and playing ball. Try out different activities to see what you like best and to add variety.

6. Use the buddy system
   Activities with friends or family are more enjoyable than doing them alone. Join a walking group, attend fitness classes at a gym, or play with the kids outside. Build a support network—your buddies will encourage you to keep being active.

7. Set goals and track your progress
   Plan your physical activity ahead of time and keep records. It’s a great way to meet your goals. Track your activities with the Physical Activity Tracker on SuperTracker.* Use the My Journal feature to record what you enjoyed so you can build a plan that is right for you.

8. Add on to your active time
   Once you get used to regular physical activity, try to increase your weekly active time. The more time you spend being physically active, the more health benefits you will receive.

9. Increase your effort
   Add more intense activities once you have been moderately active for a while. You can do this by turning a brisk walk into a jog, swimming or biking faster, playing soccer, and participating in aerobic dance.

10. Have fun!
    Physical activity shouldn’t be a chore. It can help you feel better about yourself and the way you live your life. Choose activities that you enjoy and that fit your lifestyle.


Go to www.choosemyplate.gov for more information.
Upcoming Walks

Montclair University Walk
September/October 2016
Montclair, New Jersey

Walk to End Lupus Now™
Sunday, October 23, 2016
Nomahegan Park in Cranford, New Jersey
Lupus: Learning and Living™

October 29, 2016
8:30 am - 1:00 pm

Join the Lupus Foundation of America and the Lupus Foundation of America New Jersey Chapter for Lupus: Learning and Living™, a free educational program for individuals with lupus, their families, and friends. Get the latest information on living and coping with lupus from world-renowned experts.

NYU Langone’s Hospital for Joint Diseases
301 E 17th Street
New York, NY 10003
Handicapped Accessible

Featured Speakers:

Amit Saxena, MD, Rheumatology
Alisa Femia, MD, Dermatology
Kathleen Woolf, PhD, Nutrition
Heather Milton, MS, Exercise

Thank You to Our Partner

NYU School of Medicine

Register today at support.lupus.org/lilnyc or for more information contact info@lupusnj.org or 973.379.3226.
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Medical Disclaimer / Words of Caution

We provide information in our newsletters and on our websites (the content) with the understanding that the Foundation is not engaged in rendering medical advice or recommendation. We make this information available for educational and informational purposes only, and as a benefit and service in furtherance of our mission. The information we publish is no substitute for expert medical care, and should not replace necessary consultation with a qualified healthcare professional who is familiar with your medical condition and health status. Always consult with your doctor or healthcare professional before making any change to your medical care.

Meet Our Office Staff

Leonard J. Andriuzzi, Esq., President and CEO
Julia Oppenheimer, Financial Administrator