# Chairman’s Message

Our world has changed over the past several decades. The Internet, in some ways has made our lives easier. In other ways, it has made our lives more stressful. The reality is that information is readily available through the Internet. Yet, as a Foundation that serves individuals, their families and friends, we need to provide more than just information on the Internet. We offer educational programs, resources and referrals, support services, monthly support group meetings, awareness campaigns, advocacy, access to experts in lupus and funding for research. In order to provide all of those things, we hold fund-raising events such as our walks, tricky trays, beefsteak dinners, clothing drives, dinner dances, baseball games, rummage sales, bake sales, coin drives and calendar raffles throughout the year.

I suppose, the Internet has made it easy to stay home and look up things, chat with others online, etc., but do you ever wonder how much more you could gain by being out there with us? We need your help if we are to continue to serve those affected by this debilitating disease. There are so many ways to help. We need help contacting the media to promote our events. We need help writing grant applications to companies and corporations. We need facilitators for our support group meetings. We need event volunteers to help with the fund-raising events. We need help promoting events, programs and services, on social media. We need volunteers with expertise in accounting, finances, banking, information technology (IT), social media, legal matters, human resources, website development, sales, marketing, writing, filming, photography, development/fund-raising, etc. I know that each and every one of you has some amazing talents. Will you not take the time to share your talents with us?

There are so many reasons to volunteer. Maybe it is to do your part, meet new people, join the excitement, be a positive influence, raise awareness, develop new talents, grow from the experience, learn and serve, personal satisfaction, work for a cause, be part of a team, face new challenges, pass along wisdom, keep active, and share your vision (http://www.pinterest.com/samyjobr/volunteer-quotes/). Maybe it’s good for you, reduces stress, makes you healthier, helps you gain professional experience, brings people together, promotes personal growth and self-esteem, strengthens your community, and gives you a chance to give back. Most importantly, you will be making a difference in the lives of those affected by lupus (https://students.ucsd.edu/student-life/involvement/community/reasons.html).

Maybe you are volunteering because someone you know is affected by lupus. Why you choose to volunteer makes no difference. We only hope that you can share some of yourself with us so that we can continue to grow our volunteers, our leadership and the Organization, in order to help those impacted by lupus. We want every individual living with lupus to have a better quality of life. You can help make that happen!

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**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: Somerset, Hunterdon, and Ocean, in addition, we also interested in volunteers who would like to help with occasional health fair on Saturdays.

Check out the updated Support Group Meeting Flyer in this issue of the Lupus Link!
The Summer is moving along very nicely. We have not had too many raining days (except for the first try at the Somerset Patriots’ Lupus Awareness Night), and the heat has not been too bad. People with lupus still have to be careful when exposed to the sun, even if it is not humid.

It doesn’t seem that long ago when we had the walk at Montclair State University, the fashion show in Roselle Park, the Beefsteak Dinner in Paterson, and our Rummage Sale in Little Falls. We are now getting ready for the Fall activities. We are also planning for events in the Winter and early Spring.

On Sunday, October 12, 2014 we are holding our Walk to End Lupus NowTM at Nomahegan Park in Cranford, New Jersey, and this is consistently our largest fundraiser. You can register a team or as an individual at www.lupusnj.org. We want this to be one of our best walks. We are looking for team members to each raise $100.00 per team member. This sounds like a lot, but not really. If each team member would ask a friend or relative to support their walk efforts by donating $10.00, all you need is 10 people to reach the goal of $100.00.

On November 1, 2014 the Foundation is sponsoring another educational seminar. We have asked one of our speakers to address the Affordable Care Act, and have another speaker addressing stress and its affects on those living with lupus. This event will be held at Overlook Medical Center in Summit, New Jersey.

One of our supporters, Maria Arena, is also organizing a fashion show which will be held on March 15, 2015 at the Bridgewater Manor in Bridgewater, New Jersey.

On April 16, 2015 we will be holding our annual Beefsteak Dinner, once again, featuring Uncle Floyd. This is a very popular event and a lot of fun.

I briefly addressed our rainout at the Somerset Patriots which was held on July 3, 2014, but we were able to reschedule it for August 8, 2014, and it was again a wonderful event. The people who work for the Patriots could not be kinder or more generous. When we schedule this for 2015, please come out and bring your family. It is not expensive, and the whole family will have a great time; not to mention that it helps promote lupus awareness. If you have never been to a game, you are in for a great night. We are given the opportunity to speak to the entire ballpark from home plate, and invite the people to come to our booth on the main concourse. They introduce all of our sponsors on the main scoreboard, and I am interviewed on the radio during the game.

We are now working with the New Jersey Devils, at the Prudential Center in Newark, on a lupus awareness night some time in February 2015. Details will follow in the coming months.

The Foundation is here to assist people and their families affected by lupus, and we do this by having educational seminars, attending health fairs, speaking before various groups, having support groups in Northern and Central New Jersey, helping the newly diagnosed by answering their many questions about lupus, and helping them find a doctor in their area. We are able to do this by having fundraisers, and the generous donations of our members and other generous people in the community. If you know someone with lupus introduce them to our Foundation. We are here to help. Remember that you are not alone.

—Leonard Andriuzzi, Esq.
Definitions

**Epigenetics.** Epigenetics is the modification of an individual’s DNA by other reactions. Our DNA is the same in every cell, yet we have hundreds of different kinds of cells (heart muscle, liver, bone, etc). Epigenetics turns on or off certain genes depending on whether they are required for that specific type of cell. [http://www.nature.com/scitable/topicpage/epigenetic-influences-and-disease-895](http://www.nature.com/scitable/topicpage/epigenetic-influences-and-disease-895)

**Genome-Wide Association Studies (GWAS).** Scientists look at different markers among many different people to find differences in the DNA that might be associated with a disease. This is most often used in complex diseases like lupus. [http://www.genome.gov/20019523](http://www.genome.gov/20019523)

**Personalized Medicine.** Figuring out which treatments will work best for a specific patient, based on understanding the genetics of each patient and what drives their particular disease. This would also allow us to understand if a given treatment might be more risky for certain patients. For example, trastuzumab (Herceptin) is a treatment for metastatic breast cancer. However, it only works in patients who have a mutation in the Her-2 gene. And patients who don’t metabolize (break down) azathioprine well (measured by levels of an enzyme called TPMT) should get lower doses to reduce the risk of side effects. [http://personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/pmc_age_of_pmc_factsheet.pdf](http://personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/pmc_age_of_pmc_factsheet.pdf)

**Whole Exome Sequencing.** The exome is all of the exons in a person’s DNA. The exons are the regions of DNA that tell the body to make proteins (the “coding regions.”) There are about 180,000 exons organized into about 22,000 genes. It’s now possible to sequence all of the exons and compare them to known standards, to see if there are mutations (differences) that might be causing a person’s disease. [https://www.bcm.edu/research/medical-genetics-labs/test_detail.cfm?testcode=1500](https://www.bcm.edu/research/medical-genetics-labs/test_detail.cfm?testcode=1500)

Genetics of Lupus

We know that when a family member has an autoimmune disease like lupus, other family members are more likely to get an autoimmune disease than the general population. But, even identical twins (whose DNA is identical) have less than a 50% concordance rate for lupus (that is, if one twin has lupus, the other will have lupus less than 50% of the time). So other things besides genetics (environment, hormones, epigenetics) must influence whether someone gets lupus.

Genome-Wide Association Studies have found about 35 genes that are associated with lupus. Researchers find that a given genetic marker is found more often in patients with SLE than in controls (people without lupus, but matched for age, gender and ethnicity). It is uncommon that one single gene can cause lupus. However, in rare cases, a mutation (change) in a single gene can cause (or make it very highly likely) that someone will develop lupus. Single genes are responsible for developing lupus more often in lupus that is very severe or that starts at a young age.

**The Study**

Scientists in Australia, led by Dr. Julia Ellyard from the John Curtin School of Medical Research in Australia, did whole exome sequencing of a 4-year old girl who had a stroke due to her lupus. They found a homozygous mutation (change) in the Three Prime Repair Exonuclease 1 (TREX 1) gene. This mutation caused the gene to be much less functional, and therefore, the patient’s cells produced more of a molecule called interferon-alpha. It is known that interferon-alpha is increased in patients with lupus, and there are trials of medications that attempt to lower interferon in patients with lupus.

Knowing the specific genetic cause of this patient’s lupus (and the changes in production of interferon that resulted) would allow researchers to develop specific treatments (rather than the general suppression of the immune system with drugs like steroids and azathioprine).

However, it’s important to remember that most patients’ lupus is complex, and not due to a single gene. Nevertheless, genetic studies have identified a number of genes involved in lupus, and treatments developed based on these studies are now in clinical trials.


Coping with Illness
submitted by Jason Konig, Health Educator and case manager

Caring for a loved one with chronic illness can be difficult. To better cope with the strain care giving can bring, it's important to remember to take care of your needs, too:
- Set realistic goals for yourself and focus on doing the most important things first.
- Educate yourself about your loved one’s illness to reduce fear and enable yourself to make important decisions.
- Assemble a care team.
- Recognize stress and recognize your limits.

Sun Sensitivity

Because sunshine can cause symptoms to flare, you and your loved one may have to plan your day to avoid it. "When we are going outside, we apply sunscreen several times a day," says John Forte about how he and his wife Carol, plan ahead. "The rule of avoiding 'high sun' times—from 11:00 a.m. to 3:30 p.m. - applies whenever possible. Also using a sunshade in the car when on the road, and making use of sun-resistant clothing."


Resources:

For more information about caregiving, contact:
- Caregivers-USA

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.

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!
Help Raise Funds with the LFANJ 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 website by first going through our website. 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!
**Research Updates: The Manhattan Lupus Surveillance Program (MLSP)**

Systemic Lupus Erythematosus (SLE) is a potentially fatal, heterogeneous, chronic, systemic autoimmune disease of unknown etiology. Given widely varying estimates of the incidence (number of new cases) and prevalence (number of existing cases) of SLE in the United States and the absence of data available for certain demographic groups, particularly minorities, attention has turned to obtaining a fundamental epidemiologic understanding of SLE across key race/ethnic groups. Recently, under the auspices of the National Arthritis Action Plan (NAAP), the Centers for Disease Control and Prevention (CDC) funded four state/city health departments, as well as the Indian Health Service (IHS), to more robustly define the incidence and prevalence of SLE. Results from the Michigan Lupus Epidemiology and Surveillance (MILES) and the Georgia Lupus Registry, were recently published in the February issue of Arthritis and Rheumatology. The results of the Indian Health Service Lupus Project will be published in an upcoming issue of Arthritis and Rheumatology.

The Manhattan Lupus Surveillance Program (MLSP) was initiated in September 2010 as a collaboration between the New York City Department of Health and Mental Hygiene (NYC DOHMH) and New York University School of Medicine (NYUSoM). The primary goal of the MLSP is to determine the prevalence of SLE in 2007 and incidence of SLE during 2007-09 in patients residing in Manhattan. Manhattan is unique in being the only CDC-funded surveillance site that comprises substantial populations of black, Hispanic, Asian, and white patients. Dr. Peter Izmirly, Assistant Professor, Division of Rheumatology, Department of Medicine, NYU School of Medicine, leads the project on the academic side and Hilary Parton from NYC DOHMH.

The MLSP team has been combing through medical records of the borough’s hospitals and those of private rheumatologists to gather signs, symptoms and clinical criteria for lupus. This challenging task has been aided by all of the participating rheumatologists. Thanks to the extraordinary cooperation from the rheumatologists in Manhattan, MLSP has been able to make significant progress and paint a more complete picture of the disease’s epidemiology.

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**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 web site at www.lupusnj.org or call the office at 973-379-3226. Thank your for your interest and support of the LFANJ.

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**SURVEY: What is Your Favorite Event/Program?**

Please check all that apply and return to the Foundation. Thank you.

- Chef Nikko
- Annual Beefsteak Dinner
- Coin Can Campaign
- Educational Seminars
- Monmouth Fun Day
- Glamour and Glitz Fashion Show and Gala
- Annual Meeting & Educational Seminar
- Lupus Awareness Night at Somerset Patriot’s Ballpark
- Walk To End Lupus Now™
- Other? Comments? – Please explain:

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