I spoke to Denise (Neicee) White a few weeks before the October 2013 walk, and we met briefly for the first time at the Walk. Neicee was kind enough to forward to me her biography and the copy of a song she had written called “Kisses From Heaven” dedicated to her mother, Virginia, and her sister, Vercell, who both died of complications from lupus. I interviewed her for this article to emphasize that lupus can affect not only those suffering from this debilitating and, at times, fatal disease, but it can also affect family members and friends. In this case, Neicee does not have lupus but she was forever affected by this disease and the effects that it had on her loved ones.

LJA: I understand that you were not born in New Jersey so where were you born and when did you come to New Jersey?

NW: I was born in Allentown, Pennsylvania and came to New Jersey in 1995 for a short period of time. I moved back to Allentown and then came back to stay in 2002.

LJA: Tell us about your family. How many brothers and sisters?

NW: I had five sisters: Wanda, Carolyn, Vercell, Deirdre, and Tonya (the youngest). My mother, Virginia, was a single mom who was in the healthcare industry and was a singer years before she was diagnosed.

LJA: I expect that you only had one bathroom for the five girls to share. Is that so?

NW: Actually we had one and half baths, so not too much fighting.

LJA: You told me that your mother was diagnosed with lupus. How old were you and what were her symptoms?

NW: I was eight years old when she was diagnosed, and as a little girl I remember that it seemed like she never wanted to do anything. She suffered from fatigue, kidney involvement and had problems with her brain. She was on dialysis, was hospitalized quite a lot and eventually had a kidney transplant. She would also suffer from hallucinations. During a flare up there was pressure on the brain, and the meds would make her hallucinate. It was overwhelming at times, but all my sisters chipped in to help. I had two older sisters who were in their early twenties who helped the younger sisters. I had one sister, Vercell, who at the age of fourteen, dropped out of ninth grade to help my mother raise the other two sisters. We did have an aunt, but as I said, the older children looked after the younger ones. My mother was too sick to help any of us at times.

LJA: You also told me that you have a twin sister who also has lupus. Is that right?

NW: My twin sister is Deirdre and my other sisters, Tonya, Vercell and Wanda all have been diagnosed with lupus. Only Carolyn and myself do not have lupus.

LJA: How old were your sisters when your mother was diagnosed?

NW: Vercell was 14, the two older sisters were 24 and 26 years of age. I and Deirdre were 8, Tonya was the youngest.
Interview with Neicee White

NW: When Vercell was 21 she was diagnosed with lupus. Vercell was diagnosed with kidney involvement and was on dialysis and passed away when she was 51. Deirdre, my twin, was diagnosed when she was 30. Wanda was diagnosed and has lung and heart problems. Tonya has lupus and has problems with her heart, brain and lungs. She has been in and out of the hospital about four times a year.

LJA: How did your mother’s illness affect your daily lives?

NW: They are in and out of work, suffer the flare ups, and we have to help out financially. One of my sisters is under the Family Medical Leave Act, and will not lose her job. That sister is the pharmaceutical industry. Two sisters are on disability.

LJA: When did you start getting involved with advocacy for lupus?

NW: I would say probably when Vercell died in May 2011. She had just moved to Florida because she thought the warmer weather would be better. She was wheelchair bound by that time. I was with her when she past away. She was in ICU and her kidneys had shut down, and she suffered from discoid problems and had a wound on her skin that would not heal.

LJA: Are you married and do you have any children?

NW: I am no longer married but I have three children who are all adults. A son who is 26, a daughter who is 24 and another daughter who is 22. I had them all checked for lupus, and they are free of symptoms.

LJA: What do you do for a living?

NW: I am a social worker in Somerset County, and at 22 years old I was married. I was also singing in church. I would sing as a child, and when I was 12 years old, and my mother, who sang as well, thought I had talent and tried to get me to be seen by a talent scout. That year she started to feel worse, was hospitalized and when I was 14 she passed away. My dream went to the wayside because the biggest person in my life was not there cheering me on.

LJA: When did you start singing again?

NW: When I got married I still had not resumed my singing so I could raise my family. In 2011, at the urging of my sister, Vercell, who would not let it go, I started to sing professionally. I am taking it to a whole other level and see where it takes me. Unfortunately, I did not restart my career until my sister passed away. I am going to continue to advocate for lupus wherever I can, whether at church or woman shelters.

LJA: You recorded a song?

NW: I recorded a song called “What’s Her Name” This song came about because some people were not encouraging me continue, but the song is about living your dream, pushing through whatever it is you decide to do. I am particularly proud of a song I wrote which will be released on iTunes called “Kisses from Heaven” That song was written in memory of my mother and my sister and for anyone who has lost someone because of lupus. I would like to have the proceeds go to the lupus foundation because that is where my heart is. I gave an interview on the internet, BKS1 radio, to debut my song, “Kisses from Heaven”, and I always relate the songs to what I am feeling. I sometimes feel guilty and cannot relate to what they are going through and ask why I do not have lupus? Then I think that maybe I am healthy so that I can raise awareness and support for lupus.

LJA: Would you like to add anything that I have not covered?

NW: Just that the caretaker and family members are affected, and sometimes it is a burden, it is a hardship, a hurt feeling. You see your love ones suffering and you know that there is no cure. It doesn’t have to be a death sentence, they can live a normal life if you have a team of family members, and a team of doctors that rally for them. Even sitting down in a group and sharing your feelings that you are going through with your love ones. The sad thing is that growing up we did not know about what was available to us. People would try and help with money or a gift basket, but now I have found the lupus foundation, your website and all that is available to us. I learned about the New Jersey Chapter by going to the national web site, and I wanted to get involved locally. I found your walk, and it helped. I was able to relate to people who had lupus and right next to them was a walker who did not have lupus. We were all there with the same spirit in trying to fight this giant that we face. I had a team at the walk and everyone on it was directly or indirectly affected by lupus.

LJA: Thank you for sharing your story with us and our members.
Chairman’s Message

As 2013 comes to end, I find myself reflecting on the past year. I think about how fortunate I am to be surrounded by family and friends who love and support me unconditionally. I think about how lucky I am to be able to wake up every morning, go to work and get through the day. I think about the fact that I am privileged to be in a position to help so many others through my work and through my involvement in the Lupus Community. I think about the fact that I could not get through each day without the support of those closest to me.

More than 27 years ago, a doctor told me that I had lupus. The resident, rotating through Rheumatology that month, handed me a book about lupus. The book was published in 1964 and its first sentence explained that a diagnosis of lupus meant that I only had up to two years to live. I, of course, politely returned the book to him and told him that the Hospital’s library needed to update its books. After all, it was 1986 and I was sure that progress had been made since 1964.

I quickly came to realize that not much progress had been made during that time period. I could never accept that I only had two years to live. It made no sense to me. After all, someone had just given me a name to a disease that I probably had my entire life. I now realized that the joint pain, rashes, headaches, and all of those other ailments that came and went throughout my childhood were a part of my lupus. I was thrilled to actually know that there was a name to the disease. I could finally move forward and live my life, and I did. Within days of being discharged from the hospital, I contacted the Lupus Foundation of New Jersey (now known as the Lupus Foundation of America, New Jersey Chapter, Inc. [LFANJ]) and spent the next seven years volunteering and working for the Foundation. I chose a career in Rheumatology, specifically in clinical research and continued to volunteer for the LFANJ. I could have chosen another path, but I was compelled to take this one. I chose this path because I did not want another 22 years to go by without any progress. I thought that I could make a difference by helping others, just as people have made a difference in my life.

We have come a long way since 1964 and 1986. We have achieved so much in the management of lupus, but we have not come far enough. We still have so much work to do but we need your help if we are to make a difference. There are so many ways for you to get involved. You can choose your favorite fundraising event and make it an annual affair for your circle of family and friends. You can volunteer to be part of a planning committee for one of our events or programs. You can help by creating a team for one of our lupus walks, and raise money for lupus. You can give a contribution in honor of a birthday, a bat or bar mitzvah, a communion, a confirmation, a wedding, a graduation, etc. or in memory of a loved one. You can earmark a financial contribution for a specific educational program, course memberships or research. You can help send out press releases, to various online community boards, announcing our events and programs. You can send letters to your family and friends as part of our Butterfly of Hope campaign, raising funds and awareness. You and a friend can help out for two hours at your local supermarket during our annual can drive in May. You can ask your local stores to donate in-kind gifts that can be auctioned off at some of our fundraising events. You can promote our events on your FaceBook and Twitter pages. There are hundreds of other ways to help, if you are willing to share just a bit of your time, your talents, your skills, your ideas, etc.

Our office staff does an amazing job year round, but we can do an even better job with your help. So as you reflect on this past year, give some thought as to how you can help in the coming year.

Wishing you and your families a joyous holiday season and a happy and healthy new year…

Ranit C. Shriky

President’s Message

Hello Everyone: As I write this message, we are a few weeks away from the official start of Winter. So far the Fall has been just as expected. We ran our Walk in October, ended our calendar raffle, and began our 50-50 holiday raffle. Next year we have a few new and exciting fundraisers planned. In addition to our Beefsteak Dinner with Uncle Floyd, to be held on April 10, 2014 at the Brownstone in Paterson, New Jersey, we will be holding a cooking demonstration by Chef Nikko on January 12, 2014 at the Women’s Club in Little Falls, New Jersey. The door prize will be a dinner for four, cooked by Chef Nikko, at your home. On May 4, 2014, we will be holding a walk at Montclair State University in Montclair, New Jersey, and on May 24, 2014 we will be hosting a buffet dinner and fashion show at Costa’s Restaurant in Roselle Park, New Jersey. Our summer events include Monmouth Fun Day, a day at the Monmouth Race Track in Oceanport, New Jersey and our annual Lupus Awareness Night at the Somerset Patriot’s TD Ball Park in Bridgewater, New Jersey. We are planning on three educational seminars, hopefully one in January or February, one in March and one in June at our annual meeting. In addition we will be at health fairs throughout our area in the coming months.

In setting forth our events in the beginning of this message I want you to know what is upcoming, but I have another purpose. As many older members know and newer members will ascertain, we do the fundraisers so that we can promote lupus awareness, educate the public on this disease, fund research, and maintain our office so that we can better serve the person suffering from lupus and his or her families. We are indeed a non-profit, but it takes money to keep the doors open so that we can conduct the above events so that we can better serve those in need. We do not receive any State or Federal funding, so what we raise is what we must survive on.

Our 990 State tax form, is always available to the public. In each of the past three of the last four years, including 2013, we have operated at a loss. That means that our expenses have exceeded our income. We have had to use our reserves to provide the services we provide. I have spoken to our auditor about this, and he has assured me that we are doing a good job in keeping our expenses down. The problem is, and has always been, the raising of funds through the various fundraisers that we hold. In addition, as you know, the last four years have seen the United States of America, in an economic downturn. When people lose their jobs, or their work hours are shortened, and they find that the cost of living has increased, the last thing they are thinking of is contributing part of their hard earned money to a charity. So many charities are just like us, and we are competing for the same dollars.

What I find amazing is that we have over 500 members, a board of directors and many volunteers, and on many of our events, we lose money or break even. For example the walk in the past two years has drawn over 1000 people at each walk, and this year’s walk brought in almost five thousand dollars less than last years. Our 50-50 calendar raffle, which everyone likes, ended up in the red. We had to pay out more in advertised prizes than we brought in. That is incredible. What is the problem? It is too easy to say that we do not bring in enough money. The problem with every event is that the same people raise most of the money or sell most of tickets. Once they have exhausted all of their friends and relatives, the funds stop coming in. Some members do not get involved nor do they raise any funds. Some of our members cannot financially support the Foundation, and that is understandable, but many others could help us out by selling tickets to an event or buying more than one raffle ticket. The bottom line is that we need your help to keep this foundation viable. Maybe you cannot contribute, but you know of someone who is friend or relative or a company that would like to become involved in raising funds for our foundation.

I know that it seems like I am on the psychiatrist’s couch venting my frustrations, but they say that is a good thing. I hope that you can see it in your hearts to get more involved and to help us make our events a success. Those events allow us to succeed in our mission of helping you and your families. Thank you.

Leonard J. Andriuzzi
CALENDAR of EVENTS

January 12, 2014
Healthy and Delicious Cooking
with Chef Nikko
the Women’s Guild of
Little Falls, New Jersey

Sunday, May 4, 2014
“Conquering Lupus”
to benefit LFA, NJ Chapter
In partnership with
Lambda Theta Phi
of Montclair University
at Montclair State University

March 2014
Educational Seminar
TBA

April 10, 2014
Annual Beefsteak
The Brownstone, Paterson, NJ

May 24, 2014
Glamour and Glitz Fashion Show Gala
Costa’s Restaurante Roselle Park, NJ

OUR PARTNERS

In Memoriam

Annamarie Iacono
Audrey Builock
Barbara Jean Secker
Barbara Kubin
Carmine A. Gesualdi
Cosimo Joseph Palombini
Crystal Stark
Daryn A. Vazquez
Jack Koyce
Jenna Rose McMahon
Jennie Marie Forte
John E. Woltmann
John Forte
Judith Trocan Young
Kathleen Hoffman
Lucille Macolino
Margaret Cronan
Marie Calise
Marilyn Burton
Mary Ann Canavan
Maureen Campbell
Moria Katherine Conroy
Olga Farber Dembrowski
Paul Schneider
Peter J. Salzano
Robert Long
Stephen W. Bush
Steven Rotter
Theda Evelyn D’Abronz
Victoria Tropper
Walter T. Decker, Jr.

PLANNED GIVING and LFANJ

When you are preparing your will, please consider leaving a gift to the Lupus Foundation of America, New Jersey Chapter, Inc. (LFANJ). Consult with your lawyer and accountant because you may be able to save on inheritance and estate taxes.

Making a planned gift to the LFANJ is one of the ways that you can support our mission to provide support and services for all people suffering from lupus and their families, and to find a cure. With planned giving you allow yourself to donate assets, yet defer the time we actually receive them. A bequest to the LFANJ is fully deductible for estate tax purposes. You may bequest cash, property or appreciated securities. Speak to your attorney as to the best way you can preserve your assets for your family and make a donation to the LFANJ. Thank you for your thoughtful consideration of your donation to the foundation.

-Leonard J. Andriuzzi, Esq., President & CEO
Protect Yourself This Cold and Flu Season by Dawn Isherwood, RN and Jason Konig

The cold and flu season is upon us again, and this year it has gotten off to “about the earliest start in the last decade,” according to the Centers for Disease Control and Prevention. High incidences of flu have been reported. Some of you may already have been dealing with these annual nuisances. The Foundation receives dozens of calls during flu season each year, from people with lupus worried about themselves or family members catching a flu virus or developing an infection.

When you have lupus, you have to be careful to protect yourself from viruses because they have the potential to not only make you feel horrible from the illness itself, but to cause a flare or increased activity of your lupus; providing a double whammy. The use of strong immune suppressants may put some of you at an even greater risk for contracting a virus. This is because some of the treatments used to manage lupus are supposed to suppress your immune system so that it does not produce auto (self) antibodies that may cause lupus symptoms. When your immune system is suppressed, you have the potential for increased chances of catching viruses and infections. In other words, your body is a breeding ground for those pesky germs.

So how can you best try to avoid a cold or the flu? A good place to start is to talk to your doctor about your annual flu vaccine. The early reports are that this year’s vaccine formula is a good match for the types of flu that are being reported throughout the United States. You can read more about the annual flu and pneumonia vaccines on the Foundation website.

While nothing is 100 percent fool-proof, below are some simple steps that you may help lessen the possibility of getting a cold, the flu, or any other virus include: Avoid anyone—including family members—with symptoms of fever (over 100º F), nausea, vomiting, or diarrhea. Specifically, you should avoid close, personal contact, such as hugging, kissing, and shaking hands. Wash your hands (tops, palms, and fingers) frequently with hot, soapy water for at least 15 seconds.

Remember that surfaces—especially in bathrooms, on shared office equipment, on store countertops, gas pump handles, any surface of the car, and in restaurants—can expose you to germs. Keep alcohol-based gel or wipes handy, both out in public and at home. Avoid touching your eyes, nose, or mouth. Germs spread this way. Use the crook of your arm to shield coughs and sneezing. Do not use your hands or handkerchiefs as they carry moisture that spread viruses. Stay home from work or school if you are sick. Please remember that you should never discontinue medications used to treat your lupus without first consulting with your doctor.

The Lupus Foundation of America, New Jersey Chapter, Inc. wishes you a happy and healthy holiday season. We invite you to call our health educator/case manager if you have any questions. Please visit our website at www.lupusnj.org where you will find valuable information and resources, which may help you live a better life.

Lupus Foundation of America,
New Jersey Chapter, Inc.
150 Morris Avenue, Suite 102|PO Box 1184
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Our Mission...to educate and support those affected by lupus and to find a cure.

We’re on the web!
Visit us at www.lupusnj.org!

“Do not sit back. LEAN FORWARD and GET INVOLVED - you are not alone.”

Youth Corner

We are planning on hosting a teen and youth support group meeting in January. Please contact Jason for information.

For any questions, further information, or if you are interested in joining the Facebook group, please contact me via email at jason@lupusnj.org or at the office at (973) 379.3226.

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.