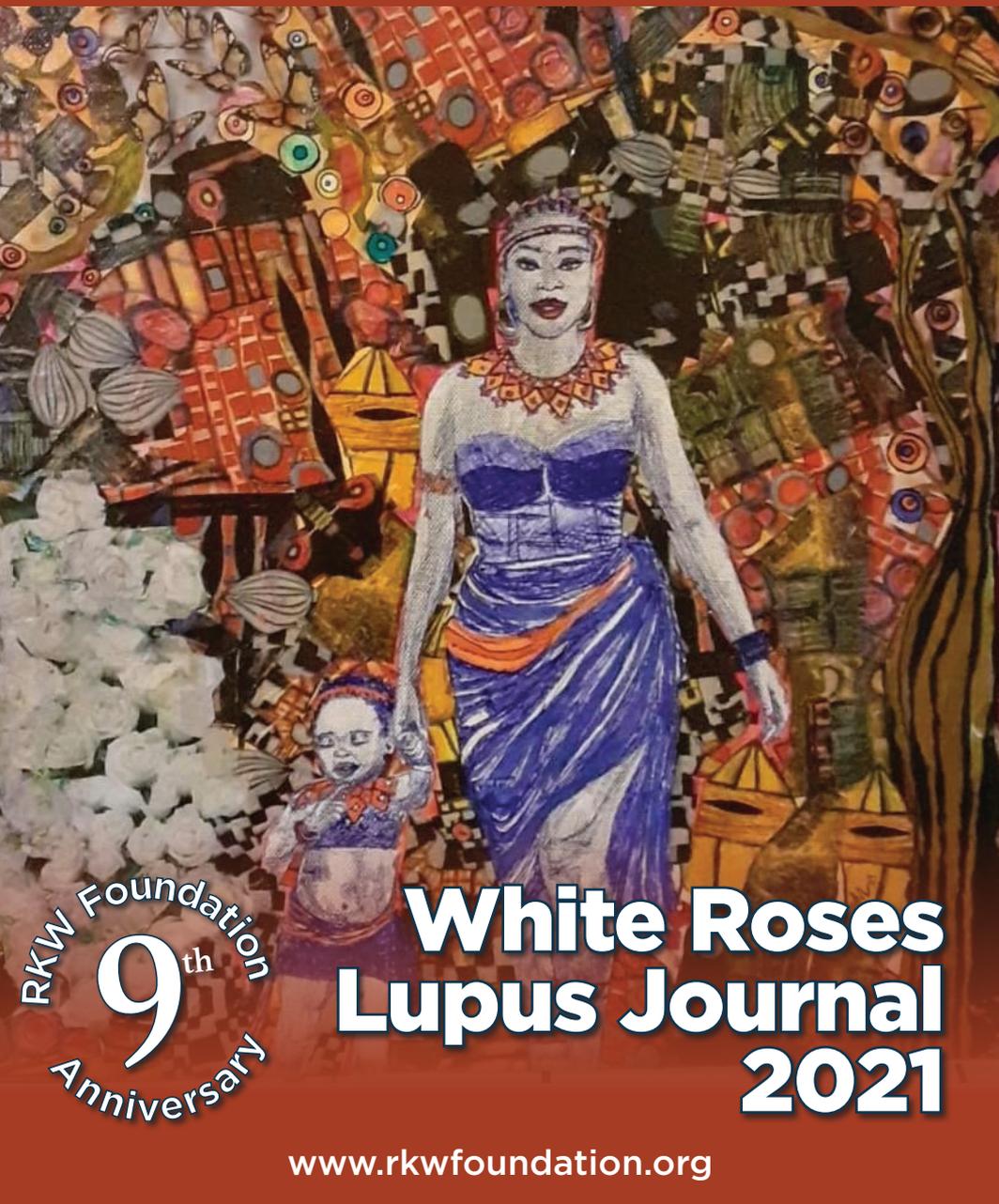




ROSEMARIE K. WITTER FOUNDATION

WHITE ROSES FOR A LUPUS CURE



RKW Foundation
9th
Anniversary

White Roses Lupus Journal 2021

www.rkwfoundation.org



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Our Mission

The Rosemarie K. Witter Foundation is a 501(c)(3) not-for-profit organization dedicated to promoting medical research in finding effective treatment, leading to a cure for Lupus. As a sponsor of the Rose Garden Scholarship Fund, your donation helps the foundation award scholarships to women afflicted with Lupus, who are pursuing a college degree in the areas of engineering, science, mathematics, medicine or law, thus assisting them financially to pursue their education.



**ROSEMARIE K. WITTER
FOUNDATION**

WHITE ROSES FOR A LUPUS CURE

*G*reetings, on behalf of the Rosemarie K. Witter Foundation, Inc., we extend our sincere gratitude for your support towards our commitment to finding effective medical treatment for Lupus and ultimately a cure, while offering scholarship opportunities to young women. The RKW Foundation is unique as we are small, however committed and determined. We are extremely grateful for all the support received during the pandemic affording us the opportunity to fulfill our mission in 2020 and 2021. As a result of this challenging time, we are forced to be creative to raise funds due to social distancing. Therefore, the RKW Team turned to technology in 2020 and created their first Virtual Wellness and Healthy Cooking Forum and first Virtual Lupus Stride; two very successful events. In 2021, we added a virtual art class RKW Paint and Sip along with the Healthy Cooking Forum and the Virtual 5K Race. All these events were successful affording us the opportunity to present "RKW Honoree Night," where we will recognize our Sponsors and 5K finalist in person and via zoom.

While we are in a Pandemic, however, continue to support Lupus research, as the work must go on. We are exposed to Lupus up close and personal. In 2002, my sister Rosemarie Karenza Witter lost the battle to this dreadful disease at the youthful age of thirty-seven, in the prime of her life, an intellectual, mechanical engineer, with hopes of attending law school. Rosemarie – affectionately known as "Rosie" – was a humanitarian who genuinely cared about her fellow man. The vision to launch this foundation came to me immediately after Rosie's passing, however it took 10 years to finally move forward. In July of 2012, the Rosemarie K. Witter Foundation, Inc. debuted as a nonprofit organization and was awarded the 501(c)(3) exempt status.

Our mission is to raise significant funds to partner with research scientist, sharing some of our observations about patterns, in particularly people with Systemic Lupus Erythematosus (SLE) (an autoimmune disease), in which the body's immune system mistakenly attacks healthy tissue. In addition, a portion of the funds raised, will assist women in college suffering from this disease, with a scholarship, who are studying in the areas of medicine, science, mathematics, and law. In 2011, BENLYSTA was the first and only drug approved to treat lupus in more than 50 years. This medicine was the first drug developed specifically for Lupus since the disease was discovered more than a century ago. The good news is that two months ago, the FDA has approved Saphnelo as a Lupus drug treatment. It is approved to treat moderate to severe disease in adults receiving standard therapy, approved to treat moderate to severe disease in adults receiving standard therapy, including oral corticosteroids, antimalarials, and immunosuppressants. Saphnelo will be available as an intravenous (IV) infusion that's administered by a healthcare professional every 4 weeks.

Other approved medications for Lupus have been borrowed from other diseases and conditions. To date there is no cure for Lupus, the goal of treatment is to control symptoms. In conjunction with your support, the RKNW Foundation, Inc. will continue to utilize various disciplinary approaches in our quest to finding effective treatment and ultimately a cure, by advocating for corporate investments (public & private) to fund our cause in pursuit of a scientific breakthrough.



In our recent communication from our lupus scientist Dr. Barbara Vilen Ph.D. -she stated " Things in the lab are moving....but very slowly. The good news is that we are near the end of enrolling SLE patients in our human study, working on data reduction and statistical analysis, and I'm beginning to write a manuscript. A lot of data to process, but the findings look good in that we can see the lysosome defect in active SLE patients. How exciting is this news and knowing that your support has made a difference in Lupus research where you can hear first-hand of how your donation has contributed to our mission.

On behalf of the RKW Foundation, we would like to extend our appreciation and sincere thanks for your participation in this charity event. We are grateful for your generosity in allowing us to bring awareness to this destructive disease – Lupus. We would like to express sincere appreciation to all our Sponsors; your commitment allows our team to focus and work towards the mission. Once again, thank you all for your committed support. I look forward to sharing some great news in the future!

Sincerely, Marcia Witter-Williams Chairperson.



About **ROSEMARIE K. WITTER**



Rosemarie K. Witter was born in Kingston, Jamaica, and grew up in New York City. She earned a degree in Mechanical Engineering, and aspired to study for a law degree. In 2002, her life was cut short by Lupus before she even got a chance to pursue her life's dream. Affectionately known as Rosie, she was a loving and caring individual, and a humanitarian who was passionate about the causes in which she believed.

Had she lived, Rosemarie would have dedicated her life to finding a cure for Lupus and supporting research to identify new therapies. Her family and friends are committed to carrying the torch, and are honored to continue her legacy.



Meet **THE BOARD**

The Rosemarie K. Witter Foundation is led by a dynamic group of dedicated professionals who are passionate about pushing the conversation around Lupus forward, and finding a cure.

MARCIA WITTER-WILLIAMS President & Founder



Marcia serves as the Chairperson of the Board of Directors and Director of Development. Marcia is currently employed as a Banking professional in the financial industry; in addition, she is a Notary Public and is an active member in her local church. Marcia's eclectic background encompasses Art & Design, Paralegal Studies and Mortgage Banking. She obtained an Executive Master's in Business Administration (EMBA) from Hofstra

University. Additional educational background consists of degrees in Fashion Design - F.I.T. (SUNY), Communication from the College of New Rochelle and a Paralegal Certificate.

SANTO CIPOLLA Vice President



Santo Cipolla has been on the Board of Directors of the Rosemarie K. Witter Foundation since its inception in 2012. Santo serves as Vice President and was the former secretary of the Rosemarie K. Witter Foundation. He became a Board Member due to his close family ties with the Witter family and his friendship to Rosie and has played an active role in the formation of the organization.

Santo Cipolla has over 37 years of experience as a paralegal. He is a native New Yorker. Born in Brooklyn and raised in Queens, he was educated through the New York City public school system and attended the City University of New York at Queens College. In 1985, he graduated from Queens College with a B.A. in Political Science/Communications. In 1986, he enrolled in the ABA Approved Queens College Paralegal Program. From 1989 until 2019, he was a member of the Advisory Board to the Queens College Paralegal Studies Program. In addition, from 1995 until 2021, he was a member of the New Hyde Park Zoning Board of Appeals. Throughout his paralegal career, he has worked in various New York City law firms and has devoted much of his career to pro bono cases involving political asylum, as well as assisting Veterans with obtaining the necessary help that they need to survive.





STACIAN FRECKLETON Director of Communication & Marketing

Stacian Freckleton joined the Rosemarie K. Witter Foundation board in 2020. The search for a cure is personal to her after losing a dear friend to Lupus, and later discovering that her goddaughter was diagnosed with this disease. Stacian has worked as a marketer in business for 20+ years. She is a proud Baruch College Alumni.



CHARLENE QUASHIE Secretary

Charlene has been a Lupus survivor for 28 years, and is an entrepreneur in both the Health & Fitness industries as well as Online Marketing. Her professional background includes working as an Administrative Assistant at a leading national law firm, and she is currently the owner of Charlene Quashie Enterprises, LLC. She holds a Bachelor of Science degree in Business Administration.



MARIA MASI Treasurer

Maria has been in the Financial Services Industry for 30 years most of which has been devoted to banking. She holds a Bachelors degree in finance from Hofstra University. Maria has a family member who is a 25 year lupus survivor.



RKW Foundation Honoree
LOREDANA MALIZIOLA, Nurse and Artist



Living with Lupus

BECAUSE I WANT TO LIVE

My name is Loredana Maliziola and I was born in Ceccano in the Lazio region of Italy. It has brought me great joy to be able to contribute my paintings for the Rosemarie K. Witter Foundation journal covers. I am Lupus survivor but it does not define me I continue to live my life with passion.

Last year I submitted a painting for a medical illness challenge in Roma Italy and I won 1st place. It was a very exciting time to be recognized for my painting and its story.

The painting describes mental illness in general. Snakes represent temptations, the slimy one that escapes the grasp, the traitor who hits you in silence, the fears we have. The disorder represented by the hand that holds the mind tightly like a vise, the huge eye for always feeling controlled by the outside world. Observing the painting we start from a dark side, at the bottom and move

up, there is also all cure by the light, above, which

represents a hope that is always there.



Painting by Loredana Ranked #1 by the painting category Community of Roma Italy.



My message to all my fellow Lupus sufferers and friends is to remember to love life and appreciate everything that life has to offer. We are a gift and because of our conviction, tomorrow will always be one more day better for us.

About the **FRONT COVER**

The work expresses the mood in strong empathy with the subject of the painting. A woman in the center of the scene holds a child by the hand, advancing proud and confident towards the viewer. The face of the serene and sunny woman symbolizes the maturity that the sufferings of life have done to her. It's represented by the tangle of colors in the background which produce in those who face them with courage and a strong sense of responsibility. The child guided by the mother for life who takes care of you and guides you towards a better future.



**A special thanks to Loredana for allowing us to use one of her paintings for the cover.*

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A man in a dark suit stands with his back to the camera, looking out a large window. The window offers a view of a cityscape with buildings and trees. The scene is brightly lit, suggesting a sunny day. In the foreground, the back of a blue conference table and several orange chairs are visible.

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Focus on Lupus **BARBARA J. VILEN, PHD**



The goals of my research are to elucidate the mechanisms that regulate immune responses to self- and foreign-antigen, and to identify how these mechanisms are dysregulated in autoimmunity and host-pathogen responses. My experience studying MHC class II gene expression with Dr. Jenny Ting, and B cell signal transduction with Dr. John Cambier, provided a broad immunology background for studies aimed at achieving these goals. Our recent studies (see #4 below) reveal that macrophages from lupus-prone (MRL/lpr) mice harbor defects in lysosomal acidification, diminishing

degradation and promoting the recycling of Fc γ R-bound IgG-immune complexes (IgG-ICs) back to the cell surface. This creates a feedforward loop wherein lysosome dysfunction results from, and leads to, chronic Fc γ RI activation. Chronic Fc γ R activation promotes autoantibody and BAFF secretion, and diminished lysosomal degradation prolongs intracellular residency of ICs. This induces phagosomes to leak apoptotic antigens and IgG into the cytosol activating innate sensors and promoting inflammation. In our collaboration with Dr. Phil Smith we are currently using mass spectrometry to assess whether chronic Fc γ RI signal transduction is the consequence of the diminished activity of SHP-1 in dephosphorylating the Immunoreceptor Tyrosine-based Activation Motif (ITAM) in the Fc γ chain of Fc γ RI. We also have an ongoing human translational study to define whether lysosome dysfunction is evident in human SLE and whether the accumulation of recycled antigens on the surface of blood cells associates with pathogenic hematopoietic subsets.

Barbara J. Vilen is an Associate Professor at the University of North Carolina at Chapel Hill in the Microbiology & Immunology Department.

POSITIONS AND HONORS

Position and Employment

1984-1986	Research Technician-University of Minnesota, Department of Medicine/Hematology, Minneapolis, MN, Laboratory of Phil McGlave MD
1986-1987	Research Technician-Mayo Clinic, Department of Immunology, Rochester, MN, Laboratory of Paul Leibson MD/PhD
1987-1993	Graduate Student-University of North Carolina-Chapel Hill, Chapel Hill, NC Thesis Advisor: Jenny Ting PhD
1994-2000	Postdoctoral fellow-National Jewish Research Center, Denver, CO, Post-doc Mentor: John Cambier PhD
2001-2007	Assistant Professor-Department of Microbiology and Immunology, University of North Carolina, Chapel Hill, NC
2008-present	Associate Professor-Department of Microbiology and Immunology, University of North Carolina, Chapel Hill, NC

Honors and Professional Memberships

1992	Lineberger Predoctoral Fellowship Award
1994	NRSA Postdoctoral Fellowship
1995	Leukemia Society Fellow Award
2000	NIAID Research Scholar Development Award
2008	Arthritis Foundation J.V. Satterfield Research Award
2009-2012	Associate Editor, Journal of Immunology
2012-2015	AAI Program Committee
2017	Rosemarie K. Witter Foundation Inc- Research Award

Contributions to Science

Overview: Our studies focus on B cell innate and adaptive immune responses during immunity and autoimmunity. We elucidated several mechanisms of B cell tolerance and identified how these mechanisms are overcome in murine systemic lupus erythematosus with ongoing studies assessing defects in human disease.

1. During my post-doc and the first years as an assistant professor my research focused on mechanisms of B cell tolerance involving the B cell antigen receptor (BCR). These studies identified that one mechanism of BCR desensitization resulted from dissociation of the Ig- α /Ig- α signal transducing complex from mu-heavy chain.

1. Subsequent co-aggregation of receptors lacking Ig- α /Ig- α with signal competent receptors attenuated BCR-mediated signaling. Mechanistically, we found that unsheathing of mu-heavy chain was required for clathrin-mediated endocytosis and delivery of antigen to the lysosome for antigen processing/presentation.
2. After my post-doc, my interest in tolerance extended to how autoreactive B cells were regulated during innate immune responses. Although TLR4 activation was known as a polyclonal activator of B cells, it remained unclear how autoreactive B cells maintained unresponsive during TLR4 stimulation since TLR4 is expressed on autoreactive and naïve cells. We found that concurrent TLR4 stimulation of dendritic cells and macrophages induced the secretion of IL-6 and soluble CD40L, which selectively repressed Ig secretion by autoreactive B cells. Mechanistically, chronic BCR signaling limited nuclear translocation of phospho-ERK. Thus, autoreactive B cells remain anergic because of receptor cross-talk between chronic BCR signaling and IL-6 receptor/CD40 signaling to regulate Ig secretion by TLR4. Current studies of B cell tolerance during innate immune activation focus on NLRC3, and its potential role as a negative regulator of Ig secretion upon innate stimulation of autoreactive B cells.
3. B cell memory is an important aspect of humoral immunity and autoreactive memory cells play a role in perpetuating autoimmune response. Our studies of B cell memory responses during immune activation to foreign antigens and pathogens identified that BAFF secretion, elicited by productive antigen-antibody immune complexes, is a key cytokine involved in upregulating Bcl-6 expression in activated T and B cells. We hypothesized that the lack of long-lasting protection following *Staphylococcus aureus* infection is disrupted because Protein A inhibits binding of immune complexes to Fc γ Rs. Instead we found that memory responses formed; however, *S. aureus* Protein A disrupted formation of long-lived plasma cells subsequently leading to a decline in *S. aureus*-specific antibody. This occurred by expanding the short-lived extrafollicular B cell response, and limiting the proliferation of B cells that arrive in the bone marrow but fail to establish in long-lived bone marrow niches.
4. Published work shows that apoptotic debris accumulates on the surface of murine and human hematopoietic cells in SLE. On myeloid cells this represents IgG-immune complexes that promote heightened BAFF secretion, autoantibody, migration of

cells to the kidney and renal disease (SLE phenotypes). Reducing BAFF to levels found in normal mice protects glomeruli from T cell infiltration and prevents renal disease. Mechanistically we find that the accumulation of ICs results from diminished acidification of the lysosome impairing degradation and promoting the recycling of FcγR-bound ICs back to the cell membrane where they accumulate and sustain FcγRI signal transduction. The prolonged intracellular residency of nucleic acid and IgG from internalized IgG-ICs leads to TLR activation and causes the phagosome to leak cargo into the cytosol, promoting activation of AIM2 and TRIM21. Mechanistically, chronic mTOR activation is central to lysosome dysfunction, and mislocalization of mTOR within MRL/lpr macrophages dysregulates caspase1/11 impeding caspase 1 activation and cleavage of Rab39a, a key event in lysosomal maturation. Our current work focuses on defining whether targeting defects in lysosomal acidification through crosslinking FcγRI with FcγRIIb is a possible lupus therapy aimed at attenuating the lysosome defect and chronic FcγRI activation. As part of that goal, we are defining whether human SLE has a similar underlying lysosome defect that might be amenable to a similar targeting strategy and lastly, we are defining how nuclear antigens accumulate on lymphoid cells.

5. Complete List of Published Work in My Bibliography:
<http://www.ncbi.nlm.nih.gov/sites/myncbi/barbara.vilen.1/bibliography/41141027/public/?sort=date&direction=ascending>



RKW Foundation Honoree
FRANK C. DELL'AMORE



Partner
Jaspan Schlesinger LLP
Attorneys at Law

Frank C. Dell'Amore focuses his practice in the areas of banking and financial services and creditors' rights. He represents and advises financial institutions, private lenders, equity fund managers, and other entities in all matters relating to foreclosure, bankruptcy, real estate, workout, loan acquisition, and general litigation and appellate matters. Frank routinely guides his clients through difficult situations

with a practical approach that is tailored to meet the varying goals and desired outcomes of his clients.

Frank regularly appears in court on behalf of clients in matters relating to distressed loan situations. While he strives to reach amicable resolutions in such matters when possible, Frank is always prepared to protect his clients' rights through litigation and other legal measures, having successfully conducted trials and framed-issue hearings, often involving challenging and unique issues of law.

He has also proven himself to be a trusted adviser to his clients with respect to creditor-related bankruptcy cases, wherein he provides guidance in all aspects of chapters 7, 11, and 13 bankruptcy matters. In this capacity, Frank has represented secured and unsecured creditors, chapter 7 trustees, landlords, and other parties-in-interest with respect to adversary proceedings, evidentiary hearings, contested plan

Education

Touro College, Jacob D. Fuchsberg
Law Center

State University of New York at
Albany

Admissions

New York

U.S.D.C., Eastern District of New York

U.S.D.C., Southern District of New York

U.S. Court of Appeals, 2d Cir.



**ROSEMARIE
K. WITTER
FOUNDATION**
White Roses for a Lupus Cure

ROSE GARDEN LUPUS SCHOLARSHIP FUND

The Rosemarie K. Witter Foundation Inc. is honored to provide a scholarship to a young woman who will be attending or is currently enrolled in a college/university and has been diagnosed with Lupus. To be eligible for consideration, applicants must meet the criteria for the scholarship guidelines as referenced in the application on our website. Ideal candidates will also have been involved in some type of charitable work, including but not necessarily limited to the fight against Lupus.

HOW TO APPLY:

Step 1

Visit our website www.rkwfoundation.org 

- Select the scholarship tab

Step 2

Fill out the application and provide the following information by **October 31, 2021**:

- Application Essay
- Letter of Recommendation
- Attend Interview with the Board of Directors

Step 3

Application review and award selection are based on:

- Eligibility Requirements
- Scholarship award grant winner will be announced on **12/7/2021** during our RKW Foundation honoree night



CONTACT US:

-  www.rkwfoundation.org
-  info@rkwfoundation.org
-  www.facebook.com/rkwfoundation
-  <https://twitter.com/rkwf4lupus>

RKW Foundation Honoree
ALAN J. JIN



Executive Vice
President
Flushing Bank

Alan J. Jin is Executive Vice President, Director of Residential, Mixed-Use, and Small Multi-Family Real Estate Lending at Flushing Bank. Mr. Jin joined the Bank in July 1998 as a Commercial Loan Officer and has held several senior management positions in the Real Estate lending area.

Mr. Jin is involved with many community and professional organizations. He is an executive council member of Good Shepherd Lutheran Church & School in Plainview, New York. He is also an active member and treasurer of CBMC, (Connecting Business and Marketplace to Christ) Long Island Chapter. He is a Board Trustee at Flushing Hospital and is an executive board member of Korean American Youth Foundation. He also serves on the Board of AREPA (Asian Real Estate Professional Association) and a past president of Metropolitan Mortgage Officers Society.

Mr. Jin resides in Plainview, Long Island with his wife and two children.



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A Pandemic Story—**THE SUNDAE PALACE**



The Sundae Palace is a small local shop that has been servicing the local community of New Hyde Park and the surrounding areas for over 40 years. They specialize in making gourmet chocolates, chocolate pops, party centerpieces, and more, as well

as, supplying chocolate making items to DIYers. When they receive an order, it is treated as if it were requested by family or friends. Additionally, the store has been an ardent supporter of the schools and organizations within the area for many years.

In 2008 three local sisters decided to purchase the business realizing how much of a staple of the community it has been over the years. Since then, they have continued supporting the local community and surrounding areas by participating in fairs and events, helping raise funds for the town and various causes. They also support and contribute to Chaminade High School which conducts Easter events by having students deliver chocolate Easter bunnies to the elderly in nursing homes. They also work with Kellenberg High School and other local organizations in their fund-raising events and endeavors. More recently, they began donating chocolates to the local Ronald McDonald House and to the families that stay there.

When the Rosemarie K. Witter (RKW) Foundation reached out to The Sundae Palace a few years ago looking for sponsorships, the decision to provide support was not hard one. The RKW Foundation was set up to help champion Lupus research which benefits so many people affected. For the owners of the Sundae Palace, it hit especially close to home because their first cousin, Loredana Maliziola, a nurse and artist, is a Lupus Survivor and has struggled with the disease for over 25 years.

During the pandemic, The Sundae Palace, like many other businesses, has struggled to stay open, but has continued to support local schools, events and organizations. It has been difficult but the community and the store's customers have helped keep the doors of The Sundae Palace open. Without the continued support of the customers, community, schools, and local organizations, The Sundae Palace could not have survived and would have surely had to shut down. Because of this local support provided to The Sundae Palace, the business has been able to keep the doors open and continue their contributions, donations, and support of local events and schools during the height of the pandemic and continues to do so.



MAURA NICOLOSI, ESQ.
AND
THE NICOLOSI LAW FIRM

ARE HONORED TO SUPPORT THE
ROSEMARIE K. WITTER FOUNDATION
IN ITS ONGOING EFFORTS TO FUND AND
FIND A CURE FOR LUPUS

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RKW Foundation Honoree
MAURA NICOLOSI



Founder—The Nicolosi Law Firm, P.C.

Maura Nicolosi founded The Nicolosi Law Firm, P.C. in 2015. Previously a partner in Nicolosi & Nicolosi LLP since 2004, she has enjoyed practicing as a general practitioner with a primary focus on real estate. Maura's experience includes all aspects of the cycle of a real estate transaction. From coops, condos and single family residences to commercial properties, Maura also represents

lenders in finance transactions. Her broad knowledge of real estate law and extensive experience with the metro New York market enables Maura to provide valuable, well-rounded advise to her wide array of clients from Manhattan to Montauk. Maura also advises various homeowners associations in Queens County in connection with the enforcement of historical covenants and restrictions that present their own unique challenges to each community.

Maura is the General Counsel of the Southampton Fresh Air Home, and a former Board Member of The Child Center of New York. She is a 1990 graduate of St. John's Law School and received her undergraduate degree from The Catholic University of America in 1987. Current bar memberships include the Queens County Bar Association, the Queens County Women's Bar Association, the Queens County Columbian Lawyers Association, and the Queens County Catholic Lawyers Guild.



RKW Foundation Honoree
MAURICE P. REILLY, MAI



Senior Vice President
Flushing Bank

President of The
Metropolitan Mortgage
Officers Society (MMOS)

Maurice P. Reilly MAI, Senior Vice President- Appraisal Director/Chief Appraisal Officer at Flushing Bank is an accomplished valuation professional with extensive experience analyzing a wide variety of income producing property

types including: Hotel/Motel, Movie Theater, New Construction, Multifamily, Mixed Use, Office and Industrial.

In addition to Mr. Reilly's expertise in the appraisal industry, he is an adjunct Professor at Fordham University and is currently President of MMOS (The Metropolitan Mortgage Officers Society). He is also a member of the Appraisal Institute.

Mr. Reilly's experience includes real estate markets on a local, regional and national level. Expert in DCF valuation modeling utilizing excel.

Due diligence and assistance with key underwriting parameters prior to appraisal engagement. Senior Real Estate Lending professional with the ability to independently operate within a larger group, while managing the day-to-day operation of the Appraisal Department to ensure compliance with all Regulatory agencies. He has strong organizational skills with the ability to adapt and incorporate new technology to further advance the efficiency of the Banks Appraisal Department. Mr. Reilly believes in supporting local charities.



SOME COMMON SYMPTOMS OF LUPUS

Central Nervous System

Headaches, dizziness, depression, memory disturbances, vision problems, seizures, stroke, or changes in behavior.

Lungs

Pleuritis, inflammation, or pneumonia

Blood

Anemia, decreased white cells, increased risk of blood clots

Heart

Chest pains, Heart murmurs

Joints

Painful, swollen joints

Kidneys

Inflammation

**It's recommended to review any information from searching the Internet with a health care professional--the primary resource to meet individual medical needs.*

LUPUS CHECKLIST

If you have systemic lupus erythematosus (lupus), every symptom matters.

With lupus, it is important to discuss all of your symptoms – even the ones you might not associate with lupus. Please complete the Lupus Checklist below and discuss these symptoms with your rheumatologist at each appointment.

SYMPTOMS	I have had this symptom since my last doctor visit	I have had this symptom for: ___ hr/days/weeks	This is the first time I have had this symptom
Example: Skin rash	<input checked="" type="checkbox"/>	3 weeks	<input type="checkbox"/>
Heart			
Chest pain	<input type="checkbox"/>	_____	<input type="checkbox"/>
Difficulty breathing	<input type="checkbox"/>	_____	<input type="checkbox"/>
Rapid and/or irregular heartbeat	<input type="checkbox"/>	_____	<input type="checkbox"/>
Lung			
Pain in the chest when deep breathing	<input type="checkbox"/>	_____	<input type="checkbox"/>
Eye			
Dry eyes	<input type="checkbox"/>	_____	<input type="checkbox"/>
Eye redness	<input type="checkbox"/>	_____	<input type="checkbox"/>
Some loss of vision	<input type="checkbox"/>	_____	<input type="checkbox"/>
Blood			
Bleeding and/or bruising easily	<input type="checkbox"/>	_____	<input type="checkbox"/>
Infections	<input type="checkbox"/>	_____	<input type="checkbox"/>
Muscles & Bones			
Muscle weakness	<input type="checkbox"/>	_____	<input type="checkbox"/>
Stiffness in joints	<input type="checkbox"/>	_____	<input type="checkbox"/>
Aching muscles	<input type="checkbox"/>	_____	<input type="checkbox"/>
Skin			
Skin rashes	<input type="checkbox"/>	_____	<input type="checkbox"/>
Sensitivity to sun or light	<input type="checkbox"/>	_____	<input type="checkbox"/>
Mouth or nose sores	<input type="checkbox"/>	_____	<input type="checkbox"/>
Hair loss	<input type="checkbox"/>	_____	<input type="checkbox"/>
Brain			
Seizures	<input type="checkbox"/>	_____	<input type="checkbox"/>
Headache and/or dizziness	<input type="checkbox"/>	_____	<input type="checkbox"/>
Memory problems or confusion	<input type="checkbox"/>	_____	<input type="checkbox"/>
Sad thoughts	<input type="checkbox"/>	_____	<input type="checkbox"/>
Weakness/numbness on one side (for example, one arm weak or numb)	<input type="checkbox"/>	_____	<input type="checkbox"/>
Kidney			
Swelling of legs and/or feet	<input type="checkbox"/>	_____	<input type="checkbox"/>
Frothy and/or bloody urine	<input type="checkbox"/>	_____	<input type="checkbox"/>
General			
Fatigue	<input type="checkbox"/>	_____	<input type="checkbox"/>
Fevers	<input type="checkbox"/>	_____	<input type="checkbox"/>
Weight change	<input type="checkbox"/>	_____	<input type="checkbox"/>
Poor appetite	<input type="checkbox"/>	_____	<input type="checkbox"/>
Other			
Other 1: _____	<input type="checkbox"/>	_____	<input type="checkbox"/>
Other 2: _____	<input type="checkbox"/>	_____	<input type="checkbox"/>



This checklist is neither a diagnostic tool nor a complete list of all possible lupus symptoms. Be sure to talk to your doctor about all of your symptoms.





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HSS

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The Department of Social Work Programs, in collaboration with the Lupus and APS Center of Excellence, brings together patients with lupus to help them and their loved ones cope with a new diagnosis, clarify treatment options, locate community resources and provide ongoing support.

Our programs are free; culturally tailored; offered in English, Spanish and Chinese; and are developmentally specific. We use a peer-based and interdisciplinary team model to enhance self-efficacy in managing lupus.

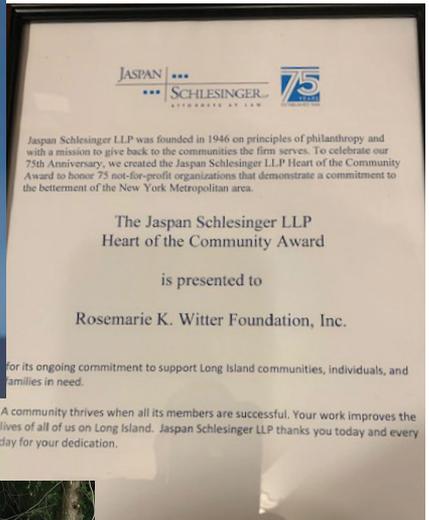
For more information, visit www.hss.edu/social-work-programs.asp

- **SLE Workshop** is a monthly education and support group, ongoing since 1985, for people with lupus, their family and friends.
- **LupusLine**® is a national telephone peer counseling service focusing on one-to-one support for people with lupus and their families.
- **Charla de Lupus (Lupus Chat)**® is a national peer health education and support program for Spanish-speaking communities with lupus including an in-person chat group for teens with lupus and their parents.
- **LANtern**® (**Lupus Asian Network**) is a bilingual (Chinese) national support and education program for Asian-Americans with lupus and their loved ones.

RKW Foundation IN THE SPOTLIGHT



Over the course of the year, the RKW Foundation has received some prominent recognition and amazing support. Among them are included the **2021 New York Charity Award**, the **Jaspen Schlesinger LLP “Heart of the Community” Award**, and recognition at the **Metropolitan Mortgage Officers Society outing**.



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as they
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TOWARD A CURE**

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LUPUS EDUCATION IS CRITICAL

Lupus is a devastating autoimmune disease that is difficult to diagnose



Patients spend an average of **4 years**



See **3 physicians** before the disease is correctly diagnosed



Can affect **11** organs

and potentially lead to irreversible damage

But it is **NOT** rare



90% are women between the ages of 15-45

2-3 times more common in people of color



To access free educational tools to diagnose, treat and manage lupus visit www.thelupusinitiative.org



RKW Foundation Honoree
MONICA FOGARTY

Certified Holistic
Wellness Health Coach
Studied Integrative
Nutrition



I'm a Life + Holistic Wellness Coach; I'm inspired by all things natural and living the healthiest and most organic life possible. My personal Journey on living a healthy life came from my own challenges and my Christian holistic focus are what brought me to taking inspired action to support others in creating a life they love.

A healthy life is more than eating healthy food and exercise, though both of those are important, everything in your life is connected: self-love, healthy relationships, inspiration and adventure, natural nutrition and exercise & energy and the ability to shine in your own unique way.

A healthy diet, prayer and meditation has been shown to be important factor in living longer and staying healthy. The perfect 360 balance.

My passion is cooking and currently I present various healthy lifestyle seminars and short videos on Instagram @organiclifebymonica.



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Living With **LUPUS**

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 Y G I L A M S D P A I N F L A M M A T I O N P C
 D Z I A K N F S L D I O R E T S O C I T R O C D
 O Q Z H S Y W O A E H I B F A G N Q E E C X H N
 B Y Z D U M L V T M E U I D H M T L I I Y B W U
 I E X A P G J Y E Q M M E O L A G D A S K I N S
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 C M S Q S O D I U M C I T R A T E R F W E R K L
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 E R Y T H R O C Y T E S E D I M E N T A T I O N
 I A J R E D B L O O D C E L L S Z Z R Q D S N K
 M D G M V J E G T R H I I O J Q F R E W C V S Z

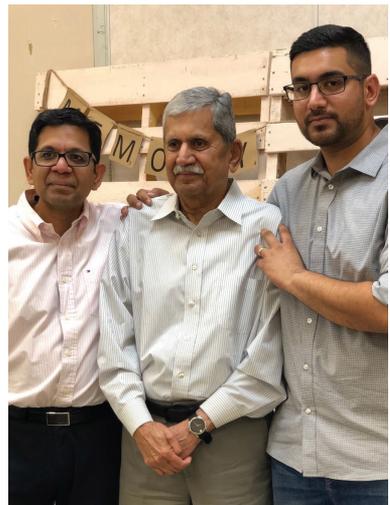
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 INFLAMMATION
 DISEASE
 LUPUS



RKW Foundation Honoree **THE ALI FAMILY**

We are happy to contribute on behalf of our cousin/niece Maryam. RKW Foundation means a lot to our family especially with the support system we receive. We hope to carry on the name of Maryam and continue to donate for an amazing cause.



Love,
Imran (Maryam's Cousin)
Salman (Maryam's Cousin)
Syed (Maryam's Uncle)

My Lupus Story **CHARLENE QUASHIE**



My name is Charlene Quashie and I am a Lupus Survivor. In 1993, I was officially diagnosed with Systemic Lupus Erythematosus - "SLE" or Lupus. Lupus was unknown to me up until that time. I learned that lupus is a chronic, autoimmune disease that can damage any part of the body (skin, joints, and/or organs inside the body). It is estimated that at least 15 million Americans have lupus. Annually, across the country, more than 16,000 new cases of lupus are reported. It is suspected that 5 million people throughout the world have a form of lupus. Lupus is mostly found

in women of childbearing age (15-44), however, children, teenagers and a small percentage of men develop lupus too. People of all races and ethnic groups have the potential to develop lupus, but women of color are two to three times more likely to develop this disease than their Caucasian counterparts.

I was a junior in college when this rash appeared on my face out of nowhere. I was concerned but not alarmed. I remember I was on summer break when my family and I saw a dermatologist in the city, who basically gave me the run around and only had the intention of selling me his product line. None of my doctors could tell me what was going on. I returned to school with questions unanswered and feeling insecure because I had what is known now as the "butterfly rash" across the bridge of my nose and my cheeks, out there for the world to see. I ended up speaking to a nurse on campus who recommended that I see a dermatologist in Albany, NY. I went to school in Alfred, NY, so that was a 4+ hour drive for a doctor's appointment. The run around was exhausting, I was upstate away from my family and my emotions were all over the place, but I knew I had to be strong throughout this process. I was determined to uncover this mystery, so I made the trip there and back by myself. The doctor examined me and right away he was certain of what it was, but wanted to verify, so he took a biopsy of my cheek and referred me to a specialist at Strong Memorial in Rochester, NY, to have additional testing. I had several of the symptoms they test for. My symptoms were: Raynaud's disease, anemia, a low white blood cell

count, butterfly rash across my nose and cheeks (prompted by the sun), protein in my urine, extreme fatigue, and unexplained hair loss. Once they realized I had protein in my urine, they suggested I have a kidney biopsy to see what stage my kidneys were in. I was in stage 3 (out of 5) which was manageable, but I needed to start treatment right away before it worsened. I was an emotional roller-coaster, I was scared because this was serious and I'm dealing with it all by myself. My mother was very worried and wanted me to get a second opinion, but a friend of hers who was a nurse explained the importance of acting fast and treating it, before things took a turn. I had a biopsy done and it showed that the lupus was very active, but with treatment it could be controlled. My family decided to come up and meet the doctor and discuss my condition. The doctor reassured all of us that with treatment I can manage my condition and live a normal, healthy life. The same doctor treated me while I was away at school up until graduation and arranged for me to follow-up with a doctor in my hometown.

One thing that I learned about Lupus is that it affects everyone differently. In most cases, lupus patients suffer from joint pains. My situation is unique, because I don't suffer from any joint pains. I don't even know when my Lupus is flaring up, unless I have blood work done to check my levels. I am thankful that I can function normally and that this disease doesn't affect my daily living, but in most cases it prevents patients from leading a normal life, in some cases, unable to hold down a job. I've noticed that I have some health issues that can't be explained and many times Lupus is to blame. Lupus is a funny disease, to this day doctors are still striving to figure it out. Many people have been misdiagnosed and are currently unknowingly living with this disease. There have been many strives made over the past 60 years for lupus, one being a new medication - Benlysta - created to treat adult patients with active lupus. Despite this victory, many patients continue to suffer, because of the lack of effective treatment. With the amount of time that has past and the numerous new cases developing each day, there is no reasonable explanation why people continue to suffer from this disease. Continuous support for medical research is still needed. As patients, we need to be our own advocates and hold doctors, researchers and congress responsible for supporting medical research to find a cure for lupus.

After I was diagnosed, I went straight into learning mode, reading and researching all that I could find about my condition and educated my family so that they wouldn't worry as much. I joined a support group that helped me tremendously to cope with Lupus. I'm so grateful for my family and friends who were there for me, even if it was just a kind,

positive gesture or words of encouragement. I'm extremely grateful for the information I was able to find that cleared up that "old school" thinking.

Since my diagnosis, I've noticed that many people are making a more conscious effort to educate the public about Lupus, instead of suffering silently with it. I've noticed billboards, advertisements, commercials, seminars, and even TV shows talking about lupus. Many celebrities have come forward to share their story as well.

For the most part, my lupus has been quiet and inactive, and my kidneys are in remission. There was a time years after my initial diagnosis that I had a flare up and my kidneys were in stage 4. At that time, I was treated with an experimental drug that worked. I also credit my health to maintaining a healthy lifestyle and exercising daily. Despite our pain and fatigue, we can find some form of exercise that will help us better manage our disease. Learning to take control of our bodies and our health puts us closer to overcoming this disease. I am truly grateful for all of the doctors, researchers and organizations that help bring us closer to learning more about this disease, how we can effectively treat it and finding a potential cure.

So much has changed over the years and we are moving in the right direction of understanding lupus and finding alternative forms of treatment. I became a member of the Rosemarie K. Witter (RKW) Foundation, Inc. because of the love and passion that's poured into the vision of this non-profit organization. Our mission is to give a scholarship to women diagnosed with lupus, enrolled in college, in a degree-granting program in engineering, science, mathematics, law or medicine, and partnering with lupus research scientist in connection with our mission to find a cure for lupus.

The main thing that has kept me going was that I decided to fight and take control of my life. I was determined to live life by my design, not allowing lupus to limit me in any way. I work a full-time job as a Legal Administrative Assistant at a leading national law firm, I'm a Team Beachbody Coach, I exercise on a regular basis, I make daily intentions of maintaining a healthy lifestyle and I promise myself to enjoy life every chance I get.

This is my story.

~ Charlene Quashie



The Impact of Lupus on the Body

Central and Peripheral Nervous System

Seizures, Psychosis, Headaches, Cognitive Dysfunction, Neuropathies, Depression, Low Grade Fever

Heart, Lungs

Pericarditis, Myocarditis, Endocarditis, Pleuritis, Pneumonitis

Kidneys

Edema, Hypertension, Proteinuria, Cell Casts, Renal Failure

Reproductive System

Pregnancy Complications, Miscarriages, Menstrual Cycle Irregularities

Blood

Anemia, Thrombocytopenia, Leukopenia, Thrombosis, Circulating Autoantibodies and Immune Complexes

Eyes and Mucous Membranes

Ulcers in the Eyes, Nose, Mouth or Vagina, Sjögren's Syndrome

Gastrointestinal

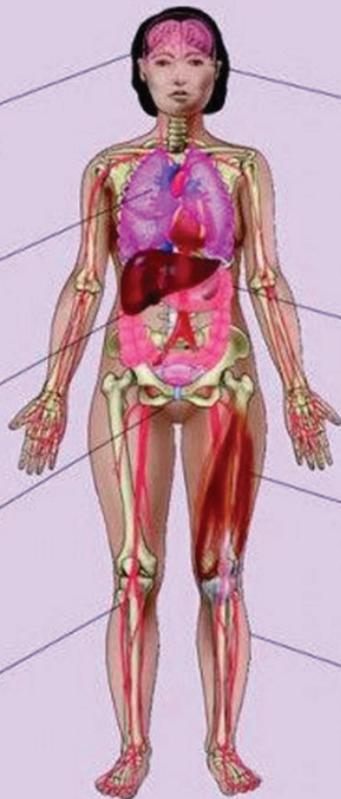
Nausea, Vomiting, Diarrhea, Weight Changes

Musculoskeletal

Extreme Fatigue, Arthralgia, Myalgia, Arthritis, Myositis

Skin

Butterfly Rash, Cutaneous Lesions, Photosensitivity, Alopecia, Vasculitis, Raynaud's Phenomenon



Lupus can affect any part of the body; however, most people experience symptoms in only a few organs.

- Lupus is an incurable chronic autoimmune disease that causes inflammation in various parts of the body. The disease can range from mild to life-threatening.
- 90% of people with lupus are women, 80% of them developed lupus between ages 15 and 45.
- The cause of lupus is unknown. Scientists believe that individuals are genetically predisposed to lupus, and that environmental factors "trigger" the symptoms.
- With proper treatment, most people with lupus can live a normal life span.

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Top Team



Nancy O'Connor
1st Place



RKW Virtual
5K Lupus
Stride
2nd Place
Winner
Photo Not Supplied



Christine Tamney
3rd Place



Joanne Orelli
4th Place

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Four Most Common Triggers of a Lupus Flare.

WEATHER



STRESS



EXHAUSTION



NUTRITION



Least Controllable

Most Controllable

Actual Quote

"I get a flare at times especially when a rainstorm hits, an extreme cold front comes around, or during extreme hot weather."

1

How much they push themselves

2

What they eat.

Actual Quotes

"Although I have always been a work-a-holic, I am learning that when my body says stop and I don't listen the only one who pays the price is me... so I am getting better at slowing it down."

"I have learned what some of my triggers are and how to ward off a severe flare. Eating healthy is a must!"



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T H U R S D A Y

MAY 27, 2021 @ 7:30PM VIA ZOOM

COST: \$45

(includes art kit that will be mailed to purchasers)
Visit: www.rkwfoundation.org for event details





Answer key—Living With **LUPUS**

B V Z Z Q P T R A E H X A O L K T L Y L Q W T M
 Y G I L A M S D P A I N F L A M M A T I O N P C
 D Z I A K N F S L D I O R E T S O C I T R O C D
 O Q Z H S Y W O A E H I B F A G N Q E E C X H N
 B Y Z D U M L V T M E U I D H M T L I I Y B W U
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 T M E N U Q T D L D O V Y Z X L G H Q O C W J L
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 E W L J Y N J B G X I W V D M P X T N T J C E O
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 HEMOGLOBIN
 ERYTHROCYTE SEDIMENTATION
 CANCER
 BLOOD
 BUTTERFLY RASH
 HEART
 JOINTS
 KIDNEY

SKIN
 EXERCISE
 BLOOD TEST
 WHITE BLOOD CELLS
 RED BLOOD CELLS
 ANTINUCLEAR ANTIBODY
 CORTICOSTEROID
 INFLAMMATION
 DISEASE
 LUPUS





**2021
ROSEMARIE K. WITTER
FOUNDATION INC.
HONOREE NIGHT**

HONOREE LIST

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Imran and Syed Ali
(Donors in Memory of Maryam Ahsan)

Monica Fogarty
(Organic Life by Monica)

Maurice Riley
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(Artist / Nurse)

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More Than 200,000 Americans Have Lupus

By Robert Preidt HealthDay Reporter
THURSDAY, Jan. 21, 2021 (HealthDay News)

Just over 200,000 Americans have the autoimmune disorder lupus, and minority women are at highest risk, according to a new study. It's the first estimate of how widespread the disease is in the United States. The number comes close to reclassifying lupus as a rare disease, defined as an illness affecting 200,000 Americans or fewer, the researchers said.

"Our study potentially redefines systemic lupus erythematosus as a rare disease in the United States and lays the groundwork for where we need to focus our efforts to reduce the burden of this disease on Americans," lead investigator Dr. Peter Izmirlly said in a news release from NYU Langone Health in New York City. He's a rheumatologist and associate professor of medicine at the health system.

In lupus (systemic lupus erythematosus), the immune system mistakenly attacks its own healthy tissues, especially joints and skin. The condition can be fatal, and often causes debilitating bouts of fatigue and pain that prevent nearly half of adult patients from working.

Previous estimates of lupus were larger but unverified.

In this study, researchers analyzed records for 5,417 adults and children diagnosed with lupus since 2002 at all U.S. state registries for the disease, as well as the Indian Native Health Service. Next, they calculated the number of people with lupus for every gender and ethnic group and applied those numbers to 2018 Census population data.

They concluded that among every 100,000 people nationwide, 72.8 had lupus, for a total of 204,295 out of a population of 330 million.

The study found that nine times more women than men have lupus, and rates were highest among Native American/Alaskan Native women, at 270.6 per 100,000.

Black women had the second highest rate (230.9 per 100,000), followed by Hispanic women at 120.7 per 100,000.

Similar racial disparities were seen among men with lupus, with American Indians/Alaskan Natives having the highest number (53.8 per 100,000), followed by Black men, at 26.7 per 100,000.

Being reclassified as a rare disease could significantly change efforts to study and treat lupus, reducing the number of study participants needed to test new treatments. It could also influence the design of clinical trials required before seeking regulatory approval for treatments, according to the researchers.

The findings could also help identify which neighborhoods or population groups need extra resources such as specialty rheumatology clinics to combat lupus.

The study was published online Jan. 21 in the journal Arthritis and Rheumatology.

More information

There's more about lupus at the Lupus Foundation (www.webmd.com/lupus/news/20210121/more-than-200000-americans-have-lupus)

SOURCE: NYU Langone Health, news release, Jan. 21, 2021

WebMD News from HealthDay

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