

Journal 2023



# ROSEMARIE K. WITTER FOUNDATION

WHITE ROSES FOR A LUPUS CURE



ANNIVERSARY 11<sup>th</sup> FOUNDATION  
RKW

## White Roses Lupus Fashion Extravaganza 2023

[www.rkwfoundation.org](http://www.rkwfoundation.org)

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is proud to support the

## Rosemarie K. Witter Foundation

and join in its mission to find  
effective treatment and a cure for Lupus.



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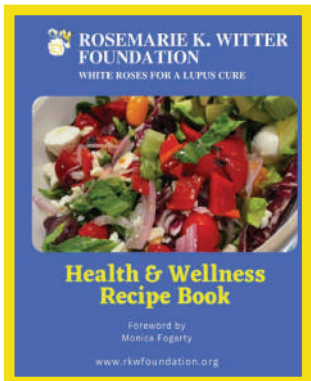
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## *Moments from our Living Life With Lupus Forum*



# OUR MISSION

The Rosemarie K. Witter Foundation is a not-for-profit organization dedicated to promoting medical research in finding effective treatment, leading to a cure for Lupus. The foundation promotes healthy lifestyles by presenting Wellness forums. As a sponsor of the Rose Garden Scholarship Fund, the foundation will award scholarships to those afflicted with Lupus who are pursuing a college degree or masters degree thus assisting them financially to pursue their education.



**G**reetings, on behalf of the Rosemarie K. Witter Foundation, Inc. as we celebrate our 11th anniversary. 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, 2021, 2022 and now 2023.

As a result of this challenging time, we are forced to be creative to raise funds. Most recent in July we presented a Healthy Wellness Forum in conjunction with HSS, Hospital for Special Surgery-Charla De Lupa Group. We continue our 5K virtual lupus stride and for the first time presenting a Fashion Extravaganza (Karenza Collection) a fashion line that is designed to help raise funds for lupus research.

As we move forward in this post pandemic climate; the RKW Team continues 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.



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 in 2021, the FDA has approved Saphnelo as a Lupus drug treatment. It is 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 RKW 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 with our lupus scientist Dr. Barbara Vilen Ph.D. stated that things in the lab are moving; she has almost completed her manuscript with next stage of successful findings. Furthermore, she stated donations are very much needed to move the positive findings she has discovered ahead. 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. We are working on new initiatives to raise funds and look forward to sharing these new ideas in 2024. On behalf of the RKW Foundation, we would like to extend our appreciation and sincere thanks for your participation in this "White Roses Lupus Gala" charity event. We are grateful for your generosity in allowing us to bring awareness to this destructive disease – Lupus. In addition, we would like to express sincere appreciation to all our Sponsors & Donors; 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.*





**ROSEMARIE K. WITTER  
FOUNDATION**  
WHITE ROSES FOR A LUPUS CURE

**HSS**

in collaboration with Charla de Lupus(Lupus Chat)<sup>®</sup> Program

INVITES YOU TO OUR

# LIVING LIFE WITH LUPUS FORUM

With special guest: Monica Fogarty, Certified Holistic Coach

**Saturday July 15, 2023 from 11am - 2pm**

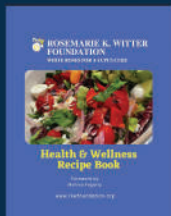
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**FREE GIVEAWAY ITEMS AND LUNCH PROVIDED**

## 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.





# STILL, WE FIGHT

*written by*

**S. Maria Salesman**

Rosemarie, brilliant was she, she was going to change the world  
I know this, because I did not know her but somehow, she is changing me  
Her presence can still be felt in the atmosphere, making sadness  
and sorrow disappear

Her heart was open, her soul was pure  
She had beauty with a purpose that could not be ignored  
But lupus got a hold of her, it took her by surprise  
It brought her down so quickly, but not without a fight  
She never gave up, she gave her best  
She fought with all her might, knowing an end was in sight  
Lupus stripped her to the core, her body could take no more  
She gave it her all, then on God she called  
He answered and took her to a better place

A place with no more pain, no more sorrows to gain, no more sadness in  
sight, no more she had to fight....ALONE

All the pain, all the tears, all the sorrows throughout the years have now  
left her body for good

But she says to tell how wonderful it feels  
Knowing ten long years have passed and gone, but her beautiful lupus  
warriors are still going strong

So, sis, even though I was private and kept my feeling close  
And that makes you wonder if what you are doing is to impose  
Know that with the help of others you are doing an awesome job, even on  
those days when you feel unsure

And to my beautiful lupus warriors, do not give up hope  
Lupus has not seen the last of us

So, while lupus has robbed me of my physical being  
And is still trying to steal survivors' beauty and self esteem

Still, we fight, fight for more  
We fight for the cure



## MARCIA WITTER-WILLIAMS

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 A. Cipolla*

**Litigation Paralegal,  
Kramer Levin Naftalis &  
Frankel LLP**

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 worked on some very prominent cases. As a litigation paralegal at Kramer Levin, Santo has worked on some of the largest bankruptcy and litigation cases around. Santo worked with Rosemarie when they were both paralegals at Curtis, Mallet-Prevost, Colt & Mosle and then at Kramer Levin where he was a member of the Bankruptcy Department before becoming the litigation paralegal coordinator and senior litigation paralegal.

Santo has also devoted much of his career to pro bono cases involving political asylum, assisting Veterans with obtaining the necessary help that they need to survive. He also teamed up with his daughter Allison and her classmates to help the homeless. They traveled throughout Manhattan and offered the homeless sweaters, warm clothes, sneakers, and food.



## 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.



## STACIAN FRECKLETON



Stacian Freckleton: **Director of Communication and Marketing** 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.



# The motivational story of the "Karenza Collection"



Marcia Witter Williams is a professional trained Fashion Designer who graduated with a degree in Fashion Design from F.I.T (Fashion Institute of Technology) in the 1980's, and subsequently worked as a successful Fashion Designer of women's wear and childrenswear fashion. As a result of the financial impact on the economy in the 80's she subsequently moved on to a career in the legal field and then Banking where she is now a Vice President in the banking industry.

In Marcia's quest to make an impact on lupus medical research by way of the Rosemarie K. Witter Foundation Inc (RKW). an organization she founded over a decade ago in honor of her late sister affectionately known as Rosie. Raising funds has been very difficult for a disease still relatively unknown to many, therefore she decided to tap into her creative inner self to launch a fashion line named "Karenza Collection" Rosie's middle name to help fund the mission of the organization. The vision of this collection is "despite adversities we strive" Living our best life each day, working, traveling, exercising. #ageisjustanumber #fashionforapurpose #selfcare #wellness

As we were emerging from the pandemic in early 2022, Marcia thought to her herself so many people are selling clothes online, many without a fashion background, perhaps she could design 1 item to sell online. However, the industry has changed since she worked as a fashion designer therefore, she decided to take a Fashion Production and Development course, visit a fashion influencer in California for a master course. This opened up a new perspective in her concept. Therefore, Marcia decided to launch a ready wear women's collection and an athleisure line. The RKW organization logo is inspired by her sister Rosie's love of white roses and the yellow butterfly symbolizing hope for a cure in lupus. This inspired Marcia's vision to design fabrics with white roses and the yellow butterfly.

The color scheme includes shades of blue, yellow and white, that includes women suits separates, athleisure wear, menswear, socks, scarfs and handbags.

To conclude, Marcia has worked vigorously to launch her amazing fashion collection entitled Karenza yours Capsule Collection 2024. Collection launch date October, 15, 2023. Visit: [www.karenzacollection.com](http://www.karenzacollection.com)



Karenza Collection<sup>®</sup>

FASHION FOR A PURPOSE

Spring Collection 2024

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# Dr. Vilen

## Lupus Research



### A. Personal Statement

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 $\gamma$ 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 $\gamma$ RI activation. Chronic Fc $\gamma$ 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 $\gamma$ 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 $\gamma$ R $\gamma$  chain of Fc $\gamma$ 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.

## B. 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 N. 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
- 2018** RoseMarie Witter Research Award



## C. 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 a 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- $\alpha$ /Ig- $\beta$  signal transducing complex from mu-heavy chain.

Subsequent co-aggregation of receptors lacking Ig- $\alpha$ /Ig- $\beta$  with signal competent receptors attenuated BCR-mediated signaling. Mechanistically, we found that unsheddling of mu-heavy chain was required for clathrin-mediated endocytosis and delivery of antigen to the lysosome for antigen processing/presentation.

a. Vilen, BJ, T Nakamura, JC Cambier. (1999) Antigen stimulated dissociation of BCR mlg from Ig-alpha/Ig-beta: Implications for receptor desensitization. *Immunity* 10: 239-248. PMID: 10072076.

b. Vilen, BJ, KM Burke, M Sleater, JC Cambier. (2002) Transmodulation of BCR signaling by transduction-incompetent receptors: implications for impaired signaling in anergic B cells. *J. Immunol.* 168:4344-4351. PMID: 11970976, PMCID: 3726184.

c. Kim, J-H, L Cramer, H Mueller, B Wilson, BJ Vilen. (2005) Independent trafficking of Ig-alpha/Ig-beta and mu-heavy chain is facilitated by dissociation of the B cell antigen receptor complex. *J. Immunol.* 175:147-154. PMID: 15972641, PMCID 3895480.

d. Kim J-H, JA Rutan, and BJ Vilen. (2007) The transmembrane tyrosine of mu-heavy chain is required for BCR destabilization and entry of antigen into clathrin-coated vesicles. *Int. Immunol.* 19(12):1403-1412. PMID: 17981794, PMCID: 3716379

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.

a. Kilmon, MA, JA Rutan, SH Clarke, BJ Vilen. (2005) Low-affinity, Smith antigen-specific B cells are tolerized by dendritic cells and macrophages. *J. Immunol-Cutting Edge* 175:37-41. PMID:15972629, PMCID: 3724409.

b. Kilmon, MA, NJ Wagner, AL Garland, L Lin, K Aviszus, LK Wysoc ki, BJ Vilen. (2007) Macrophages prevent the differentiation of autoreactive B cells by secreting CD40 ligand and interleukin-6. *Blood* 110:1595-1602. PMID: 17712049; PMCID: 1952615

c. Gilbert, MR, Wagner, NJ, SZ Jones, AB Wisz, J Roques, KN Krum, S-Y Lee, V Nickeleit, C Hulbert, JW Thomas, SB Gauld, and BJ Vilen. (2012) Autoreactive pre-plasma cells break tolerance in the absence of regulation by dendritic cells and macrophages. *J. Immunol.* 189: 711-20. PMID: 22675201, PMCID: 3392546.

d. Lee, S-R, Rutan, JA, MA Kilmon, NJ Wagner, SZ Jones, SH Clarke, and BJ Vilen. (2012) Receptor cross-talk spatially restricts p-ERK during TLR4 stimulation of autoreactive B cells. *J. Immunol.* 189: 3859-68. PMID: 22984080; PMCID: 3466401.

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 $\gamma$ 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.

a. Gohlke, PR, Williams, JC, Vilen, BJ, Dillon, SR, Tisch, R, GK Matsushima. (2009) The receptor tyrosine kinase MerTK regulates dendritic cell production of BAFF. *Autoimmunity* 42:183-97 PMID: 19301199, PMCID: 2892231

b. Kang, SA, AB Keener, SZ Jones, RJ Benschop, AC Maldonado, JC Rathmell, SH Clarke, GK Matsushima, JK Whitmire, and BJ Vilen. (2015) IgG-immune complexes promote B cell memory by inducing BAFF. *J. Immunol.* 196: 196-206. PMID: 26621863; PMCID: 4684997

c. Keener, AB, LT Thurlow, NA Spidale, KM Cunnion, R Tisch, AR Richardson, and BJ Vilen. (2017) *Staphylococcus aureus* Protein A disrupts long-lived plasma cell-mediated immunity. *J. Immunol.* 198:1263-73. PMID: 28031339, PMCID: PMC5266639.

d. Kang, SA, AB Keener, SZ Jones, RJ Benschop, AC Maldonado, JC Rathmell, SH Clarke, GK Matsushima, JK Whitmire, and BJ Vilen. (2015) IgG-immune complexes promote B cell memory by inducing BAFF. *J. Immunol.* 196: 196-206. PMID: 26621863; PMCID: 4684997

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 Fc $\gamma$ R-bound ICs back to the cell membrane where they accumulate and sustain Fc $\gamma$ RI 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 Fc $\gamma$ RI with Fc $\gamma$ RIIb is a possible lupus therapy aimed at attenuating the lysosome defect and chronic Fc $\gamma$ RI 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.

a. Kang, SA, JL Rogers, A Monteith, C Jiang, T Tarrant, R Roubey, M Dooley, R Falk, J Schmitz, M Diaz, G Fedoriw, and BJ Vilen. (2016) Apoptotic debris accumulates on hematopoietic cells and promotes disease in murine and human SLE. *J. Immunol.* 196:4030-9. PMID: 27059595, PMCID: 4868781

b. Monteith, AJ, SA, Kang, E Scott, K Hillman, Z Rajfur, KA Jacobson, MJ Costello, and BJ Vilen. (2016) Defects in lysosomal maturation facilitate the activation of innate sensors in SLE. *Proc Natl Acad Sci USA* 113: 2142-51. PMID: 27035940. PMCID: 4839468

c. Kang, SA, G Fedoriw, K Kikly, M Diaz, BJ Vilen. (2017) BAFF induces lupus nephritis by promoting T cell entry into the glomeruli. *J. Immunol.* 198:2602-11 PMID: 28235864. PMCID:5360485

d. Monteith, AJ, HA Vincent, SA Kang, P Li, TM Claiborne, NJ Moorman, BJ Vilen. (2018) mTORC2 activity disrupts lysosome acidification in systemic lupus erythematosus by impairing caspase-1 cleavage of Rab39a. *J. Immunol.* 201:371-382 PMID: 29866702, PMCID: 6039264

- a. Kang, SA, JL Rogers, A Monteith, C Jiang, T Tarrant, R Roubey, M Dooley, R Falk, J Schmitz, M Diaz, G Fedoriw, and BJ Vilen. (2016) Apoptotic debris accumulates on hematopoietic cells and promotes disease in murine and human SLE. *J. Immunol.* 196:4030-9. PMID: 27059595, PMCID: 4868781
- b. Monteith, AJ, SA, Kang, E Scott, K Hillman, Z Rajfur, KA Jacobson, MJ Costello, and BJ Vilen. (2016) Defects in lysosomal maturation facilitate the activation of innate sensors in SLE. *Proc Natl Acad Sci USA* 113: 2142-51. PMID: 27035940. PMCID: 4839468
- c. Kang, SA, G Fedoriw, K Kikly, M Diaz, BJ Vilen. (2017) BAFF induces lupus nephritis by promoting T cell entry into the glomeruli. *J. Immunol.* 198:2602-11 PMID: 28235864. PMCID:5360485
- d. Monteith, AJ, HA Vincent, SA Kang, P Li, TM Claiborne, NJ Moorman, BJ Vilen. (2018) mTORC2 activity disrupts lysosome acidification in systemic lupus erythematosus by impairing caspase-1 cleavage of Rab39a. *J. Immunol.* 201:371-382 PMID: 29866702, PMCID: 6039264
- e. SA Kang, Saxena-Beem S, K Grier, ME Clowse, L Arbeevea, SZ Sheikh, JL Rogers, BJ Vilen. Lysosome dysfunction is evident in active SLE and precedes the accumulation of surface immune complexes on activated naïve (DN2) B cells.  
**Manuscript in prep.**

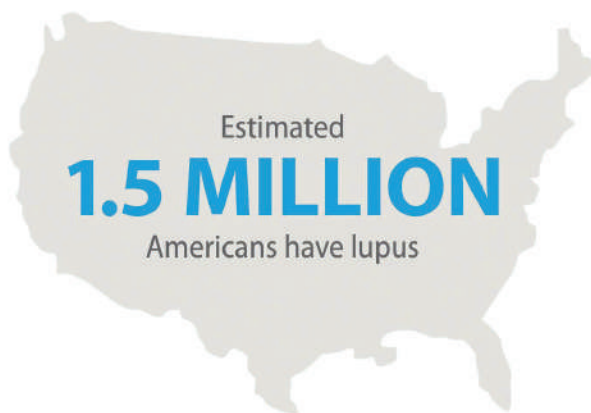
## Patents

1. **Issued patent:** Product and method for treatment of conditions associated with receptor-desensitization. **Patent #00914700.0-2116.** Issued 2002.
2. **Issued patent:** Compositions and Methods for Repressing B cell Autoantibody Secretion and Treating Autoimmune Disease. **Patent # 8,795,653; Issued 2014.**
3. **Provisional patent:** Composition and Methods for Crosslinking Fc Receptors. National Phase Filing **Ref. No.: 5470-825; Ref. No.: 17-0011.** May 2019.

## 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>

# THE IMPACT OF LUPUS IN AMERICA



**90%** of people with lupus are women.  
Men can also develop lupus.



**15%**  
of individuals  
diagnosed  
with lupus  
are children.

Name: \_\_\_\_\_ Date: \_\_\_\_\_

# Lupus

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

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 1.5 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 was 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 strides 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, medical 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 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 not-for-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 major sports organization, 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**



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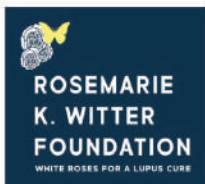
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Our mission is to empower the ambitious, bold working individuals who are living their best life despite adversities by providing quality and trend setting fashion collection to compliment their trend setting lifestyles. The Fashion House of MWW was inspired by a sister (Marcia) who lost her sister Rosemarie Karenza Witter affectionately known as "Rosie" to the dreaded disease lupus. Rosie loved sophisticated fashion with clean lines. In searching ways to fund her founded nonprofit, Marcia rekindled her design passion and profession after three decades by launching this fashion line in aid of supporting the mission of the Rosemarie K. Witter Foundation Inc a 501 (c)(3) nonprofit organization. The (RKW) foundation logo consists of white roses; Rosie's favorite flowers and a yellow butterfly signifying hope for a lupus cure. This logo inspired the designer, significantly reflected in the Collection. Rosie's middle name was Karenza, therefore the first collection is named Karenza Collection. This is another way to keep her memory alive while making significant impact in lupus research.

[www.karenzacollection.com](http://www.karenzacollection.com)

## OUR MISSION

### *Rosemarie K. Witter Foundation*

Rosemarie K. Witter Foundation, Inc., is a not-for-profit organization dedicated to promoting medical research in finding effective treatment, leading to a cure for Lupus. The foundation promotes healthy lifestyles by presenting Wellness forums. Through our sponsors of the Rose Garden Scholarship Fund, the foundation will award scholarships to those afflicted with Lupus who are pursuing a college degree or master's degree, thus assisting them financially to pursue their education.

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o!Select the scholarship tab

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- o!Attend Interview with the Board of Directors

### Step 3

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- o! Scholarship award grant winner will be announced on during our RKW Foundation honoree night



#### CONTACT US:

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[lupus.org](http://lupus.org)

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# Joanne Mustapich

Vice President, Sr. Marketing Manager



Ms. Mustapich is an accomplished marketing, advertising, and communications professional who currently serves as vice president, senior marketing manager at Flushing Bank. Joanne Mustapich develops, designs, manages, and leads the implementation of successful integrated marketing strategies that encompass all communication elements. Prior to joining Flushing Bank in 2010, Joanne worked at Harman International Industries, Inc., for almost 12 years as director of marketing (Harman Kardon) and corporate media director (Harman Consumer Group). She is a creative and collaborative leader with a commitment to excellence and relationship building. Joanne has served as a volunteer for the American Diabetes Association, American Heart Association, Juvenile Diabetes Research Foundation, and the National Multiple Sclerosis Society.

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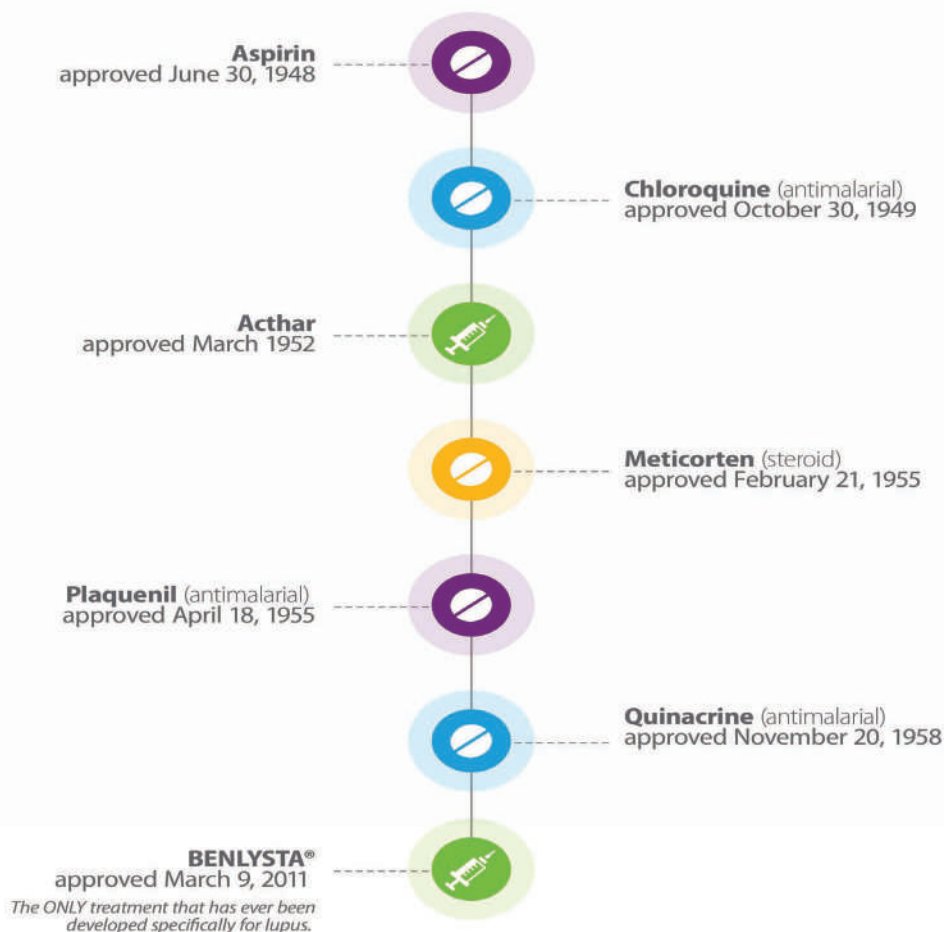
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# Kareen Althea Windross

On the island of Jamaica, a beautiful force of nature came into being, supported by the rich culture of strict family ties and the Adventist faith.

Kareen Althea Windross, Colleen as she is affectionately called, was gifted by the creator with a multitude of talents. Cognizant of that fact, she did not rest on her laurels but proceeded to explore them all. As a gifted student with an aptitude for Math and Science and an endearing love for people, she thought of pursuing medicine. The instrumentation involved in medicine—needles specifically and her adversity of blood halted her pursuit, but the Creator had other plans.

To say that Colleen is talented is an understatement; she is gifted in many fields. Her mother was the inspiration that fed her passion for craftsmanship and style. It was her keen observation of the arduous nature of the constructive dressmaking process that seeded her passion for pattern making, ultimately fashion design.

Colleen attended the world renowned FIT - Fashion Institute of Technology, New York; while there she studied pattern making and fashion design, acquiring an Associate degree in the respective fields. Colleen went on to work with a bridal fashion house, and ultimately founded her own clothing line 'Juxtapose'. Make no mistake and call her a dressmaker, as she will emphasize that she paid for her degree.

As we all know, she is a notable fashion designer. For those of us who know her well, we are aware of her flair, her ability to wear her own clothing with pizzazz, coupled with dazzling hairstyles.

Colleen continued her Michelangelesque rise and became a teacher of Mathematics, in both Junior High School and High School, respectively. There, she taught a variety of students. Those that were gifted enjoyed her expertise in advanced Mathematics, including pre-calculus. Intrigued by math phobic students, she worked diligently to rid them of the phobia by simplifying the mathematical steps which helped them to view math favorably. This was all due to her Bachelor's degree in Finance which she received from Bernard Baruch College, New York and a Master's degree in math education from Hunter College, New York.

In 1994 at the Ark, in Brooklyn, Colleen presented her first fashion show; Who-dini performed at the inaugural event. The event provided great exposure; Colleen was sought after by brides who desired unique wedding ensembles. She not only created the gowns but the dresses for the entire bridal party. Additionally, many young ladies sought her expertise in creating "one of a kind" prom dresses. One such dress, not surprisingly, graced the cover of 'Prom Guide Magazine', in 1998.

For most people, this would appear to be enough but not for the energetic, scintillating, Colleen. She is also a spin master, a DJ, a lover of music. Although she employs music as a bridge in academia, she will tell you that she cannot sing to save her life. She incorporates music into her classroom activities as she relates with her students. Her favorite song in this regard is 'Level Up' by Ciara.

We all know how excited Colleen is about traveling and willingly shares her experiences with a good dose of advice. A self described, "Jack of all trades, yet a master of all." Colleen aspires to ultimately own a museum which will showcase her designs.

In addition to all that was mentioned, Colleen is a mother of three; she adores her children and delights in their success. Family is paramount to her, she loves all that she does and credits God for keeping her going. Colleen can be seen on her YouTube channel Kwross patterns and her Instagram page @kwross\_patterns. Her many interest also extend to baking, crotcheting, painting, dancing and 5K races.

We cannot conclude without speaking about Colleen's radiant smile and her favorite Einstein quote which expresses a life long philosophical view. "If A is success in life, then  $A = x + y + z$ . Work is x, play is y and z is keeping your mouth shut."

Colleen will boldly tell you, "Fashion is my passion, numbers I shrink, music is my life and God keeps this energizer bunny going."

We delight in honoring the quintessential pattern maker, fashion designer, educator, disc jockey and offer her all of God's rich blessings for continued success.





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For more information, visit [www.hss.edu/social-work-programs.asp](http://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.
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- **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.





# INTERNSHIP PROGRAM INFORMATION

The Rosemarie K. Witter Foundation Inc is now recruiting interns. Students who are looking to gain real world experience by applying their knowledge to a charitable cause, are encouraged to apply. This UNPAID internship offers you the opportunity to gain class credits, while contributing to our mission of finding a Lupus cure.

This internship is open to STUDENTS from all backgrounds and majors. We are looking for interns for the Fall 2023 and/or Spring 2024 semesters.

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- ✓ Willing to attend director's meetings once a month (necessary to receive credit for internship).
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