



ROSEMARIE K. WITTER FOUNDATION

WHITE ROSES FOR A LUPUS CURE



RKW Foundation
7th
Anniversary

White Roses Lupus Gala 2019

www.rkwfoundation.org

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Monday & Wednesday
Tuesday, Thursday-Saturday
Sunday

10:00 a.m - 7:30 p.m.
10:00 a.m - 6:00 p.m.
Closed

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 would like to 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 RKKW Foundation is unique as we are small, however committed and determined. 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 young 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 truly 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. On 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 and is the first and only drug approved to treat lupus in more than 50 years. This medicine is the first drug developed specifically for Lupus since the disease was discovered more than a century ago. Currently approved medications for Lupus are 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.

The RKW Foundation Inc. is proud to serve as a major contributor to Lupus research as recently published in the Journal of Immunology Vol. 201, Issue 2 15 Jul 2018. In addition, the foundation launched its first free Lupus Research Forum in NYC in October 2018. At this forum, the foundation presented its research scientist of choice, Dr. Barbara Vilen, who answered questions about the research and development of treatments for lupus. This event empowered the Lupus Survivors in attendance

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 the 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 near future!

Sincerely,

Marcia Witter-Williams, Chairperson



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 Director of the Marketing & Communication Committee as well as the Chair of the Board of Directors. Marcia is currently employed as a mortgage banking professional in the financial industry; in addition, she is a Notary Public and participates in her local church as a member of the Session Board. Marcia's eclectic background encompasses Art & Design, Paralegal Studies and Mortgage Banking.

She recently received 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 serves on the Public Relations Committee as well as the Marketing and Communications Committee. He has a background in Communications and works as a litigation paralegal for a major New York City law firm. In addition to working on the Rosemarie K. Witter Foundation as Vice President and on the Public Relations Committee, he also serves as the Foundation's official photographer.

Santo has been a member of the Queens College Paralegal Studies program for the past 30 years as well as a member of the New Hyde Park Zoning Board of Appeals for the past 24 years.

LORRAINE ALLYSO-GOVAN Director



Lorraine is a native of South Africa, and is a founding director of the Rosemarie K. Witter Foundation. She chairs the Educational Advisory committee. Lorraine's professional background is Social Work, and she has more than 15 years experience in her profession. She holds a degree in Counseling Psychology from the College of New Rochelle.





MALIYA CHERELUS Director

Maliya Chairs the Development Committee and oversees the Event Planning Committee. She has over 30 years experience in banking industry as well as 10 years in radio broadcasting. Maliya's community involvement extends to other charitable organizations and Service projects She is a Senior Loan Servicing Officer in a New York based financial institution. Maliya has a degree in Business Administration and Psychology from New York University.



CHARLENE QUASHIE Secretary

Charlene has been a Lupus survivor for 22 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.



Living with Lupus **BECAUSE I WANT TO LIVE**



My name is Loredana Maliziola and I was born on June 27, 1973, in a small town in Lazio, Italy called Ceccano. It has been an honor to paint the cover portraits for the RKW Foundation for the last 2 years. Today I work as a nurse in the psychiatric field, a job which I love and do with great passion.

As a child, I was always in good health. At the age of 15 I suddenly became ill and, in fact, did not even realize I had a disease. A team of doctors in Rome referred to me as a "strange case" and even suspected it was leukemia. For one year I was given high doses of cortisone (deltacortene strong 100mg per day) which caused the marrow to reproduce so the leukemia had been resolved.

At the age of 28, there was a short a period of my life in which I had happiness, but the thought my illness returning was always like a dark cloud on the horizon. At this time, I finally would have my dream come true. I was married and going to have the family I desperately wanted. I was awaiting the birth of my child - a son that we would name Alessio. Unfortunately, during the pregnancy, I developed five thromboses despite the anticoagulant therapy I was on (I had used warfarin for years). Sadly, the thrombosis had attached itself to the placenta and affected my son by impeding his breathing. Throughout the pregnancy, we were all aware of the risks and many doctors closely monitored me. Unfortunately, it was not enough for both of us. My son did not survive the pregnancy, and I would find myself in intensive care again fighting for my life. They had uncovered that the cause of the death of my son was my Lupus illness.

- Persistent exhaustion and weariness
- Photophobia - sensitivity to light/sun
- Irritability
- Renal/Kidney issues and diseases - Glomerulonefrite
- Calcium deficiency
- Circulatory problems
- Blood Pressure issues
- Severe joint pain
- Low-grade fevers
- Persistent Headache
- Anemia

Today we know the symptoms and difficulties of the disease, which I have also suffered from, include:

To this day, I continue my therapy sessions and take a variety of medications including an immune suppressant, which includes antirejection drugs used in transplant patients. Now, I am fine, mostly because I want to live my life! In the past 10 years I feel blessed, even with this illness. My passions now consist of painting portraits of women and taking in puppies for which I find homes. My puppies are my family, they help me feel better and they are there for me, always keeping me company no matter how I'm feeling. 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.



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



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



The goals of my research are to elucidate the mechanisms that regulate B cell 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 reveal that lupus-prone (MRL/lpr) macrophages harbor defects in lysosomal acidification,

diminishing degradation and promoting the recycling of FcγR-bound IgG-ICs back to the cell surface. Chronic FcγR activation from recycled ICs promotes autoantibody and BAFF secretion, and prolongs intracellular residency of ICs due to their lack of degradation. This induces phagosomes to leak apoptotic antigens and IgG into the cytosol activating AIM2 and TRIM21. Our future goals are to define the upstream events that fail to regulate FcγRI signal transduction and to characterize the events that disrupt lysosome acidification. My experience in studying murine SLE, my background in signal transduction, the established clinical collaboration, creates a strong team, which make us well-suited to carry out future projects.

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

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-a/Ig-b signal transducing complex from mu-heavy chain.

Subsequent co-aggregation of receptors lacking Ig-a/Ig-b with signal competent receptors attenuated BCR-mediated signaling. Mechanistically, we found that unshoothing 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 FcγRs. 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.



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NADJÉ Leslie

Nadjé Leslie was born and raised in Kingston, Jamaica and thanks her parents for getting her started on the violin at 7 years old. She has trained with Paulette Bellamy and Dr. Lisa Walker since then.

Nadjé fell in love with performing at a young age having been exposed and trained in dance, drama and of course, music.

Nadjé is undoubtedly one of Jamaica's most outstanding young musicians advancing to the World Stage in 2006 after winning the enviable title "Junior Instrumental Grand Champion of the World" in Hollywood, California. During the competition she received gold medals and a special Industry award.

She was crowned National Instrumental Champion in the Jamaica Cultural Development Commission (JCDC) Festival after being awarded several gold medals. (2006)

Nadjé was also awarded the Prime Minister's Youth In Excellence Award and the Kiwanis Youth In Excellence Award in succeeding years. To learn more, visit www.nadjeviolin.com.



Rose Garden Scholarship Recipient

KALPANA BANIIYA



A new young girl in America with full of responsibilities, anxious about extortionate medical bills which her father cannot afford. Hair loss, weight gain, fifteen prescribed pills a day and unlimited hospital visits; I was physically and mentally tired. After endless visits to the cancer center, the doctor finally informs me about my diagnosis with Lupus. My family became hopeless as I was the only hope in their lives, being the only member in the household with the capability of speaking decent



English. One of the hardest things I had to do as a thirteen year old was translating to my parents the life threatening disease I was diagnosed with, and even to this day, they do not sufficiently understand Lupus. Fatigue, medication side effects, frequent absences, and bullying inflict a huge barrier in my education. I isolated myself from friends and family as I started to give up on my capabilities. It still amazes me how drastically my life changed when high school began. I realized I was more than a Lupus patient, developing a passion inside me. I originated by joining a cross country. Later, I was part of seven different clubs, including the National Honors Society. Additionally, I am now an Ambassador of the Lupus Foundation of America. I am a huge Lupus advocate as I participate in many Lupus advocacy events. Moreover, I am currently working on creating a support group for Lupus fighters on my campus. I am also a founder of the Nepali Youth Mentoring Program, to assist first-generation students with the college process. Finally, I am extremely grateful for this opportunity and I believe I am an ideal candidate as I refuse to waste any possibility that is given to me, therefore I will make complete use of this. Additionally, I am a hard working first generation student who comes from a low income household, therefore this scholarship can be truly powerful to my education, turning my dreams into a reality.

"I am extremely grateful towards RKW foundation for recognizing my hard work and believing in my capabilities. I am a freshman at Middle Tennessee State University, majoring in biology. I aspire to pursue a career in the medical field and provide service to unrepresented places. Coming from a low income household, being a first-generation college student and living with an autoimmune disease, I experience a lot of self-doubts on a daily basis. The foundation's contribution to my education has not only reduced my financial burden but also increased my confidence to reach my goals."



ROSEMARIE K. WITTER FOUNDATION INC.

ROSE GARDEN LUPUS SCHOLARSHIP FUND



ROSEMARIE
K. WITTER
FOUNDATION
WITH HOPE FOR A LUPUS CUR

The Rosemarie K. Witter Foundation Inc. is honored to provide scholarships to young women 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 criterias for the scholarship guidelines as referenced in the electronic application on our website. Enrolled in a degree-granting program in engineering, science, mathematics, law, or medicine. In addition we have added scholarships to be given for other degree concentrations. 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:

Please visit our website www.rkwfoundation.org and select the Scholarship Tab. The Scholarship process includes the following:

- Application Essay
- Letter of Recommendation
- Interview
- Eligibility Requirements
- Application Deadline 09/01/19
- Scholarship award granted



Contact Us

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Outstanding Sponsorship

FRANCIS W. KORZEKWINSKI

Frank Korzekwinski is Senior Executive Vice President, Chief Real Estate Lending Officer of Flushing Financial Corporation and Flushing Bank. He joined the Bank in 1993 after serving in other capacities for both banking and investment banking organizations. He is currently responsible for overseeing all real estate lending related business activities including commercial real estate and residential/mixed-use real estate lending, loan servicing, portfolio management, collections



and foreclosure related activities as well as loan work outs and the disposition of other real estate owned. Under his leadership, the Bank's real estate assets have grown to more than \$5 billion.

Throughout his 30 plus year career in banking, Frank has been active with various professional and community organizations. Giving back to communities and organizations has always been a priority for Frank. He has served on the Board of Directors for Holy Cross High School and currently serves on the Board of Directors for the Faith Home Foundation. Over the years he has been active in charitable fundraising initiatives for Holy Cross High School, the American Cancer Society, Helen Keller Services for the Blind, the Child Center of New York, the Korean American Youth Foundation and Sharing and Caring.



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Community Service Award **AURORA HIRSCHFELD & THE SUNDAE PALACE**

The Sundae Palace is a small shop that has been servicing Long Island and Queens New York areas for over 40 years. They make gourmet chocolates, chocolate pops, and centerpieces and provide chocolate making supplies...all are made with the love and care by the talented staff.



The Sundae Palace is a local supporter to the schools and organizations within the area. So when 3 years ago we were approached regarding contributing to the Rose Marie K Witter (RKW) Foundation it was an easy YES. The RKW Foundation helps to support Lupus research which would benefit my first cousin. She has been a Lupus survivor for 25 years and continues fight her battle even today. She is the artist that has provided the paintings for the last 2 journal covers. Her passions for painting and taking in stray dogs to find homes for them has never lost it stride, even during her long hospital stays.

The Sundae Palace treats each order as if they are making for their own family and friends.

We were established by a mother and daughter partnership. In 2008 it was purchased by another family this time it was us 3 sisters that grew up in the neighborhood. We had always been into making edible favors most chocolates for those special events for family and friends. We visited the store for supplies so it seemed to be the perfect fit when the previous owner was ready to sell.

Today The Sundae Palace provides much more than just chocolates. Whether a wedding, new baby, birthday or anniversary, they will make your memorable event even sweeter. We continue to support our community but have also expanded out to causes that impact and touch our lives.



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Outstanding Service **GERTRUDE SCHEIWGER**

Gertrude Schweiger (Trudy to her clients/friends) is a German born accountant and tax preparation professional that has been working in finance for over 30 years. She became an Enrolled Agent and started her own accounting business in 2000, and has built a sizable client base of individuals and companies.

Trudy is well known by her clients to be the go-to person for all financial questions, and there are very few accounting issues that she doesn't have experience solving.

After meeting a person who suffered with Lupus, Trudy felt compelled to support the search for a cure and has volunteered her accounting services to the RKW Foundation since 2014.



Congratulations!

Proud to support the RKW Foundation

LUPUS

What is it?

Lupus is an autoimmune disease in which the immune system attacks its own tissues and causes widespread inflammation and tissue damage in the affected areas. Lupus is characterized by periodic episodes of inflammation (flare ups) of and damage to the joints, tendons, other connective tissues, and organs, including the heart, lungs, blood vessels, brain, kidneys, and skin. The effects of the illness range from mild to severe. There is no cure for lupus, but medical interventions and lifestyle changes can help control it.

SIGNS & SYMPTOMS



Sources:
www.mayoclinic.org
www.cdc.gov
www.hopkinsmedicine.org
www.stanfordhealthcare.org

healtheo360[®]



Living With **LUPUS**



SUNLIGHT
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TIRED
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STRESS
FLARES
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CHRONIC
CELLS
STIFFNESS
SWELLING
WOMEN

Alejandro **OLMEDO**

Alejandro Olmedo's opera career began with the opportunity to sing live for Plácido Domingo in 1987. He dedicated a popular Mexican song in honor of Mr. Domingo who was impressed with the beauty and quality of his voice and encouraged Alejandro to study and train seriously for a career in opera. Alejandro took Mr. Domingo's advice and began studying voice with Francisco Cassanova and Gustavo Marquez, music with Scott Wiles.



In 1995, he entered the Operalia in Mexico City and became a semi-finalist. At the 1997 Operalia contest in Tokyo, he was a finalist. Mr. Domingo then introduced Mr. Olmedo to Bruno Pola, the internationally acclaimed Italian baritone. Mr. Pola became Alejandro's teacher and mentor. Mr. Olmedo also coached in operatic repertoire with Jeffrey Goldberg (Metropolitan Opera), Gene Bullard, zarzuela specialist Pablo Zinger, Aldo di Tullio, and Metropolitan Opera conductor Richard Weitach.

Alejandro traveled to Italy, Switzerland, Germany, Sweden and Finland for five consecutive summers to continue his vocal studies with Mr. Pola. In 1998, at the invitation of Mr. Plácido Domingo, Alejandro sang for King Juan Carlos of Spain, and his wife, Sofía, Queen of Spain. His current vocal coaches in New York are Metropolitan Opera Assistant Conductor Lucy Arner and Luigi Veccia.



Roseanne **ACKERLEY**

Hailed by critics as a singer with “commendable stage presence,” a “pleasingly intense, well placed voice” and “personal sparkle,” soprano Roseanne Ackerley has distinguished herself by her exceptional singing and her flare for dramatic and emotional characterization. This season, Ms. Ackerley sang Brangäne in *Tristan und Isolde* with TundiProductions Wagner Summer Festival in Vermont. Upcoming engagements include Sieglinde in *Die Walküre* with TundiProductions and singing “Una poenitentium” soprano soloist in the Mahler’s 8th Symphony with Windham Orchestra (VT.)



In previous seasons, Ms. Ackerley sang the title role in *SuorAngelica* with Miami Lyric Opera, covered the title role of *Tosca* with Long Island Lyric Opera sang *Nedda* in *I Pagliacci* with East Harbor Opera in NY and *Donna Anna* in *Don Giovanni* with Vocal Productions, NYC. Ms. Ackerley was the soprano soloist in Rossini’s *Petite Messe Solenne* with the Westchester Chorale, *Micaëla* in *Carmen* with New Rochelle Opera and *Desdemona* in *Otello*, *Magda* in *La Rondine* with Opera Company of Brooklyn. Ms. Ackerley performed the title role in *Suor Angelica* with Garden State Opera, *Micaëla* in *Carmen* with Miami Lyric Opera, *Antonia* in *The Tales of Hoffman* with Opera Company of Brooklyn and was the soprano soloist for Mendelssohn’s *Elijah* and Beethoven’s *Christus am Ölberge* with the Westchester Oratorio Society. Ms. Ackerley has performed leading roles with Connecticut Grand Opera, Teatro Grattacielo at Lincoln Center, Opera in the Heights, Union Avenue Opera, New Jersey Association of Verismo Opera, New Rochelle Opera and Bronx Opera among many others. Her signature roles include *Rosalinde* in *Die Fledermaus*, *Liù* in *Turandot*, *Mimi* in *La bohème*, *Hanna* in *The Merry Widow*, and *Micaëla* in *Carmen*. Ms. Ackerley is a recipient of the Richard Gold Career Grant and the New York Foundation of the Arts Career Grant. She received her Master of Music degree in Vocal Performance from Mannes College the New School for Music in New York.

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.



HSS offers more lupus support and education programs than any hospital in the United States.

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.

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WHITE ROSES LUPUS GALA

Schedule of Events

- 3:30p.m. - 4:30p.m. Cocktail hour , Silent Auction & Raffle Prizes
- 4:40p.m. Welcome and Introductory remarks- Marcia Witter-Williams, President
- Host: Sharon Brown - Greetings
- Dinner served
- Alejandro Olmedo -Opera Singer
- Dr. Barbara Vilen, PHD- Lupus Research Scientist Presentation
- Microbiology and Immunology, University of North Carolina at Chapel Hill, NC
- Musical interlude by award winning Violinist, Nadje
- Charla De Lupus (Lupus Support Group)
- Presentation of the White Roses Honoree Awards, by Santo Cipolla, Vice President
 - Outstanding Sponsorship Support - Flushing Bank Video presentation and honoree recognition to Frank Korzekwinski
 - Community Service Award-Sundae Palace - Video presentation and honoree recognition to Aurora Hirschfield
 - Outstanding in-kind service Award- Gertrude Schweiger, EA - Accountant honoree recognition for in kind service
 - Alejandro Olmedo & Roseanne Ackerley - Duet
- Silent Auction announcement and Raffle drawing
- Kalpana Baniya - Presentation of 2019 Rose Garden Scholarship Recipient Award Winner
- ONI-BODI: Eva Thomas, CEO/Founder
- Musical interlude by award winning Violinist, Najee Anthony Leslie
- Presentation of Certificates of Recognition for Outstanding Support
- Acknowledgment of our Sponsors
- Musical interlude by award winning Violinist, Najee Anthony Leslie
- Closing remarks

Music by DJ Roy IRIE JAM Radio 93.5FM

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What is LUPUS?

Presented by the
Lupus Awareness Group of Guam



LUPUS PATIENTS' IMMUNE SYSTEMS
KILL HEALTHY TISSUES INSTEAD OF GERMS.

LUPUS IS **NOT** CANCER OR AIDS.
IT IS NOT CONTAGIOUS.

THREE MAIN TYPES OF LUPUS:

- 1 SYSTEMATIC
- 2 DISCOID
- 3 DRUG-INDUCED

3

HOW CAN I COPE WITH LUPUS?

- Pay attention to your body
- Slow down if you're tired
- Pace Yourself
- Don't blame yourself for your fatigue
- Consider support groups and counseling
- Stay involved in activities
- Practice meditation and yoga
- Exercise & Eat Healthy



WHO GETS LUPUS?



- Anyone
- More women get Lupus than men
- With good care, women with Lupus can have a healthy baby!

WHAT CAUSES LUPUS?



We don't know.
We are still researching.
There is no known cure.
It can be managed.
Lupus runs in the families.



HOW DO I FIND OUT IF I HAVE LUPUS?

- Medical History
- Complete Physical Exam
- Lab Testing of Blood and Urine
- Skin or Kidney Biopsy

Not a single test can show if you have Lupus.
Doctors have to run several tests.

It may take time for a doctor to diagnose Lupus.

COMMON SIGNS OF LUPUS:



WHAT IS A FLARE?

-When symptoms appear, it is called a flare.

To Prevent A Flare:

- Limit the time you spend in the sun.
- Maintain a healthy diet.
- Develop coping skills to help limit stress.
- Get enough rest and quiet.
- Exercise moderately when possible.

LUPUS
GUAM

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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

www.medmd.org

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

Lisa GATHRIGHT

Lisa Gathright is both a visual and performing artist. The daughter of renown soul and folk musician William Gathright, Lisa has been highly influenced by music throughout her life. Performing under the stage name “Willie Wright” from 1960s through the 1980s, Lisa’s father is considered to be one of the most gifted singers, song writers and musicians of his era. So gifted, that his cult album, *Telling the Truth*, a remarkable fusion of folk music, jazz, soul and pop music, originally released in 1977, has recently been re-released at the consistent urging of his fans. “Music has



had a big influence on me. I used to play my father’s albums when I was young, and that allowed me to escape into another world full of colors, shapes, tones and unlimited possibility. When I look over my life, I find that music – particularly folk, soul and jazz – also helped me to express and to deal with various experiences and emotions. All of this is represented in my visual work,” Gathright remarked.

The inspiration for “Canvas-sation: Expressions of Art” came to Gathright while on a trip in Spain in the summer of 2015, during which time she joined her sister Sheila (a musician and vocalist who works



and lives in Europe) in a series of mini musical concerts held at her sister’s home in Mallorca. Gathright added, “I’m a storyteller like my father. I really wanted to start a discussion with this exhibition about freedom that comes with stepping out and taking chances, to do the things that you want or need to do, despite life’s challenges. I believe that everyone will be able to find a bit of themselves in my work, as well as a celebration of a life well lived.”

“Perception”
by Lisa Gathright



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Eva THOMAS

Eva Thomas is the CEO/ Founder of **ONI-BODI**, LLC a beauty, health and wellness company. She is manufacturer of all natural skin care products made with the essential oils extracted from “roots of nature”, plants, and herbs. ONI-BODI skin care products are dedicated to developing high quality, hand-blend products to exfoliate and



remove dead skin cells, extract the impurities with detox mask applications while replenishing and restoring your skin naturally.

Eva is a Licensed Massage Therapist with a degree in Occupational Science she received while attending New York College of Health Professions, and her focus is on “Medical Massage Therapy” . She has treated many patients with diseases and disorders such as parkinsons, cervical dystonia, herniated discs, scoliosis, arthritis, osteoporosis, thyroid, and many more. She incorporates, Swedish, Asian Bodywork, Reflexology, Trigger Point Therapy, to name a few. Eva believes the Holistic Approach to wellness is important because, it is treating the mind, body, and spirit as a “whole” not just the symptoms of a medical condition.

Eva also a graduate of Bernard Baruch College where she holds a BA in Corporate Communications, with the focus on Broadcasting, Media, and Communications. She had the privilege of interning at CBS and worked on several documentaries that aired on channel 2. Eva, however, found herself intrigued with the stock market, and the financial institutions.’ She also a Business Analyst and currently works for a top Mutual Fund and Asset Management Company, where she currently holds a Securities Law License(series 63), Mutual Funds License(6) Life and Health Licenses. She has worked on the trading floor and has executed trades in the billions on an institutional level . Eva is also a licensed esthetician(skin care therapist) where she is able to provide additional services, such as Hydrodermabrasion, Microdermabrasion, Glycolic Peels, Herbal Extracts, Makeup Application, Eyelash extensions, Eyebrow sculpting, Back Facials, and treat hyperpigmentions of the skin like rosacea, mylasma and many more.

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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Charlene **QUASHIE**

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 made arrangements 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, 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 an 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.

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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Managing LUPUS



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



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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LUPUS IN WOMEN

Out of 1.5 MILLION Americans with Lupus, 90% are women between the ages of 15-44.

Women of color are 2-3 times more likely to get Lupus than Caucasian Women.

Lupus is the leading cause of premature cardiovascular disease, kidney disease, and stroke among young women.

70% of the Lupus cases are SLE, 10% Cutaneous, 10% drug-induced.

6 years is the average length of time it takes to get a Lupus diagnosis

Most Common Symptoms of Women with Lupus:

- Anemia
- Fatigue
- Fever
- Hair loss
- Mouth sores and ulcers
- Muscle pain
- Painful joints
- Pain or change of color in the fingers when it's cold
- Rashes
- Sun sensitivity
- Swollen glands
- Swollen joints

63% Of Lupus patients are incorrectly diagnosed at first

Lupus is **MORE** common than AIDS, Cerebral Palsy, Multiple Sclerosis, Cystic Fibrosis, and Sickle Cell Anemia combined.

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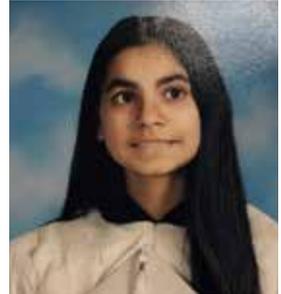
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PATIENT FACT SHEET

Lupus



CONDITION DESCRIPTION

Systemic lupus erythematosus, referred to as SLE or lupus, is a chronic (long-term) disease that causes systemic inflammation which affects multiple organs.

When healthy, our immune system protects the body from germs and cancers. With lupus, the immune system misfires and attacks "self," the patient's own tissues, in a process called autoimmunity or "loss of self-tolerance."

Most often, lupus starts in young females in their fertility age, although it can sometimes start during childhood (see section on Childhood-onset lupus below). The disease is more common in some ethnic groups, mainly blacks and Asians, and tends to be worse in these groups.

About 20% of people with lupus develop the disease as children or teens. When lupus starts in childhood, it is called childhood-onset SLE, or cSLE. It is rare to get lupus before age 5 years.



SIGNS/ SYMPTOMS

People with lupus often have symptoms that are not specific to lupus. These include fever, fatigue, weight loss, blood clots and hair loss. They may also have heartburn, stomach pain and poor circulation to the fingers and toes. Pregnant women can have miscarriages. Lupus can flare during pregnancy and can affect its outcome. The American College of Rheumatology has a list of symptoms and other measures that doctors can use as a guide to decide if a patient with symptoms has lupus.

- **Rashes:**
 - butterfly-shaped rash over the cheeks - referred to as malar rash
 - red rash with raised round or oval patches - known as discoid rash
 - rash on skin exposed to the sun

- **Mouth sores:** sores in the mouth or nose lasting from a few days to more than a month
- **Arthritis:** tenderness and swelling lasting for a few weeks in two or more joints
- **Lung or heart inflammation:** swelling of the tissue lining the lungs (referred to as pleurisy or pleuritis) or the heart (pericarditis), which can cause chest pain when breathing deeply
- **Kidney problem:** blood or protein in the urine, or tests that suggest poor kidney function
- **Neurologic problem:** seizures, strokes or psychosis (a mental health problem)

- **Abnormal blood tests such as:**
 - low blood cell counts; anemia, low white blood cells, or low platelets
 - positive antinuclear antibodies (ANA) result: antibodies that can cause the body to begin attacking itself that are present in nearly all lupus patients
 - certain abnormal antibodies: anti-double-strand DNA (called anti-dsDNA), anti-Smith (referred to as anti-Sm), or antiphospholipid antibodies

Lupus flares vary from mild to serious. Most patients have times when the disease is active, followed by times when the disease is mostly quiet - referred to as a remission. Yet, there is much reason for hope. Improvements in treatment have greatly improved these patients' quality of life and increased their lifespan.



COMMON TREATMENTS

The treatment goals are to suppress the overactive immune system and ultimately induce remission and prevent permanent organ damage. The types of medications required will depend on the symptoms. Treating cSLE requires close monitoring by a rheumatology team experienced in caring for children with lupus. Common treatment options include hydroxychloroquine (Plaquenil), corticosteroids and immune suppressants. Other medications help control pain, including nonsteroidal anti-inflammatory drugs (NSAIDs) like ibuprofen or naproxen. In 2011, the FDA approved a biologic, belimumab

(Benlysta), for the treatment of active SLE in adult patients and it was approved in 2019 for use in children.

All medications have possible side effects. You should discuss the benefits and risks of recommended medications with your doctor. Based on the response to treatment, your doctor may be able to adjust medications to lower side effects while still controlling the lupus. It is very important that you discuss with your medical team any concerns you have about your medicines, or any changes to your medicines you are considering, to ensure the lupus is treated adequately.



CARE/ MANAGEMENT TIPS

Most people with lupus can live normal lives. Treatment of lupus has improved, and people with the disease are living longer. A good doctor-patient relationship and support from family and friends can help you cope with this chronic and often unpredictable illness. Learn as much as you can about lupus, your medications and what kind of progress to expect. Take all your medications as your doctor prescribes, and visit your rheumatologist often to prevent serious problems. This lets your doctor keep track of your disease and change your treatment as needed.

Stay active. Exercise helps keep joints flexible and may prevent heart disease and strokes. Avoid excess sun exposure. Sunlight can cause a lupus rash to flare and may even trigger a serious flare of the disease itself. When outdoors on a sunny day, wear protective clothing (long sleeves, a big-brimmed hat) and use lots of sunscreen.

If you are a young woman with lupus and wish to have a baby, carefully plan your pregnancy. With your doctor's guidance, time your pregnancy for when your lupus activity is low. While pregnant, avoid medications that can harm your baby.

Children with cSLE

Hearing that your child has lupus can be frightening. However, by understanding the disease and working closely with the health care team, you can learn how best to take care of your child.

There may be times when children and teens with lupus must take time off from school to allow their bodies to heal. Otherwise, they are encouraged to live as normal a life as possible. Going to school, playing with friends, exercising, having a healthy diet and continuing family activities are all important.

Updated March 2019 by Suleman Bhana, MD, and reviewed by the American College of Rheumatology Committee on Communications and Marketing. This information is provided for general education only. Individuals should consult a qualified health care provider for professional medical advice, diagnosis and treatment of a medical or health condition.

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