

Engaging Diverse  
Participants in  
Lupus Clinical Trials:  
The Path  
Forward



# Program Booklet

Friday, July 21, 2023  
11:00 am – 4:00 pm ET

AMERICAN COLLEGE  
of RHEUMATOLOGY  
*Empowering Rheumatology Professionals*

# TABLE OF CONTENTS

WELCOME ..... 3

SPONSORS ..... 4

AGENDA ..... 5

SPEAKER BIOGRAPHIES ..... 8

RESOURCES ..... 20

# WELCOME

Engaging Diverse Participants  
in Lupus Clinical Trials:  
The Path Forward

AMERICAN COLLEGE  
of RHEUMATOLOGY  
*Empowering Rheumatology Professionals*

Dear participants,

On behalf of the planning committee, we welcome you to Engaging Diverse Participants in Lupus Clinical Trials: The Path Forward. We are incredibly excited to have gathered such a distinguished group of lupus researchers, medical professionals, industry experts, patient advocates, and individuals affected by lupus to engage in meaningful discussions and collaborations.

The importance of equitable clinical trials in advancing lupus research and improving patient care cannot be overstated, and your presence here demonstrates your commitment to making a difference in the lives of those living with this condition. Profound disparities by race, ethnicity and socioeconomic status persist and ensuring diverse access to inclusive trials with genuine community partnerships has the potential to change the way lupus is treated and reduce disparities in outcomes.

Over the course of this summit, we have curated a program that encompasses a wide range of topics related to lupus clinical trials. From innovative approaches in patient engagement and referral practices to national trends.

By bringing together stakeholders from various healthcare domains, we have endeavored to provide a comprehensive platform that fosters insightful discussions and facilitates connections that will drive forward the frontiers of lupus research. Moreover, this summit offers a unique opportunity for networking and collaboration. We encourage you to actively engage in conversations in the afternoon breakout session to share your experiences and learn from your peers as we collectively strive towards improving the lives of patients with lupus.

We would also like to express our heartfelt gratitude to the speakers, presenters, staff, sponsors, and patients who have generously contributed their expertise, time, resources, and experiences to make this summit a reality. Your dedication and support are invaluable, and we are immensely grateful for your involvement.

In closing, we would like to extend our best wishes to all participants, may your discussions be insightful, your collaborations fruitful, and your endeavors contribute to the advancement of lupus research and patient care. Together, let us make a meaningful difference in the lives of those affected by lupus.

Welcome once again and thank you for joining us on this important journey.

## The Planning Committee

**Allen Anandarajah, MD, MBBS**, University of Rochester Medical Center

**Irene Blanco, MD, MS**, Northwestern University

**Charmayne Dunlop-Thomas, MS, MPH**, Emory University School of Medicine

**Candace H. Feldman, MD, MPH, ScD**, Brigham, and Women's Hospital

**Sarfaraz A. Hasni, MD, MSc**, National Institute of Arthritis and Musculoskeletal and Skin Diseases

**Rosalind Ramsey-Goldman, MD, DrPH**, Northwestern University

**Saira Z. Sheikh, MD**, University of North Carolina School of Medicine

Engaging Diverse Participants  
in Lupus Clinical Trials:  
The Path Forward 

Friday, July 21, 2023  
11:00 am – 4:00 pm ET

Thank you to our sponsors!

 **Bristol Myers Squibb™**

**Genentech**  
*A Member of the Roche Group*

 **Remegen**

AMERICAN COLLEGE  
of RHEUMATOLOGY  
*Empowering Rheumatology Professionals*



# AGENDA

Engaging Diverse Participants  
in Lupus Clinical Trials:  
The Path Forward

AMERICAN COLLEGE  
of RHEUMATOLOGY  
*Empowering Rheumatology Professionals*

Friday, July 21, 2023

11:00 am – 4:00 pm Eastern

11:00 – 11:05 AM	<b>ACR Welcome and Opening Remarks</b>	<b>Douglas White, MD, PhD</b> ACR President Chair of Rheumatology, Head of the Rheumatology Research Lab Gundersen Health System
11:05 – 11:10 AM	<b>Greetings, COIN Committee</b>	<b>Rosalind Ramsey-Goldman, MD, DrPH</b> COIN Chair Gallagher Research Professor of Rheumatology Northwestern University Feinberg School of Medicine
11:10 – 12:00 PM	<b>Panel A: Patient Perspective in Lupus Clinical Trials</b>	<b>Stacey Kennedy-Conner</b> FACE Specialist, Lupus Representative, Member of Patient Advocates for Lupus Studies at Lupus Therapeutics Chicago Public Schools  <b>Aleta McLean, LPC</b> Senior Director of Client Services and Outcomes Tracking Open Hands Atlanta  <b>Monique Gore-Massy</b> National Lupus Advocate/Global Patient Consultant #LemonadeMaker  <b>Moderator(s):</b> <b>Christele Felix</b> LupusChat Chief Operating Officer  <b>Charmayne Dunlop-Thomas, MS, MPH</b> Emory University School of Medicine Associate Director Research Projects
12:00 – 12:30 PM	<b>Keynote Address: Diversity and Clinical Trials</b>	<b>RDML Richardae Araojo, PharmD, MS</b> Associate Commissioner for Minority Health Director of the Office of Minority Health and Health Equity U.S. Food and Drug Administration  <b>Moderator:</b> <b>Sarfaraz A. Hasni, MD, MSc,</b> National Institute of Arthritis and Musculoskeletal and Skin Diseases Director Lupus Clinical Research

# AGENDA

Engaging Diverse Participants  
in Lupus Clinical Trials:  
The Path Forward

AMERICAN COLLEGE  
of RHEUMATOLOGY  
*Empowering Rheumatology Professionals*

12:30 – 1:15 PM

## Panel B: Promising Practices in Lupus Clinical Trial Diversity and Awareness

**Saira Z. Sheikh, MD**

Linda Coley Sewell Distinguished Professor of Medicine  
University of North Carolina School of Medicine

**Pamela Payne-Foster, MD, MPH**

Professor of Community Medicine and Population Health  
University of Alabama - Tuscaloosa

**Joy Buie, PhD., MSCR, RN**

Director of Research  
Lupus Foundation of America

### **Moderator:**

**Allen Anandarajah, MD, MBBS**

University of Rochester Medical Center  
Professor of Medicine

1:15 – 1:30 PM

## Break

ACR Informational Slides

1:30 – 2:15 PM

## Panel C: The Role of the Pharmaceutical Industry in Diversification of Clinical Trials

**Sergio Arce, MD, PhD**

Medical Director, Global Clinical Development, Autoimmune Diseases  
RemeGen Biosciences, Inc.

**Coby Hobar, MD**

Clinical Development Lead  
Bristol-Myers Squibb

**Jodi Bridge Hons.B.Sc**

Senior Clinical Operations Lead Gazyva in Rheumatology/ Nephrology  
Hoffmann-LaRoche Limited

### **Moderator:**

**Kenneth Kalunian, MD**

UC San Diego Health  
Professor of Clinical Medicine

2:15 – 2:20 PM

## Breakout Session Transition

**Rosalind Ramsey-Goldman, MD, DrPH**

ACR, COIN Chair  
Gallagher Research Professor of Rheumatology  
Northwestern University Feinberg School of Medicine

2:20 – 3:20 PM

## Breakout Session: Roundtable Discussions

---

**Session 1: Engaging communities and building genuine long term relationships**

**Candace Feldman, MD, MPH, ScD**  
Assistant Professor of Medicine  
Harvard Medical School, Brigham and Women's Hospital

---

**Session 2: Creating a network of trial sites in underserved communities**

**Ashira D. Blazer, MD, MSCI**  
Assistant Attending Physician and Assistant Professor of Medicine  
Weil Cornell Medical College Hospital for Special Surgery

---

**Session 3: Developing a diverse pool of investigators and staff**

**Irene Blanco, MD, MS**  
Professor of Medicine  
Northwestern University Feinberg School of Medicine

---

**Session 4: Providing sustainable support and standardized platform**

**Donald Thomas, MD, FACP, FACR, RhMSUS**  
Clinical Associate Professor of Medicine; Uniformed Services University of the Health Sciences  
Arthritis and Pain Associates of P.G. County

---

3:20 – 3:50 PM

## Breakout Session Report Out

### Speaker(s):

Breakout Session # 1  
Candace Feldman, MD, MPH, ScD

Breakout Session # 2  
Ashira D. Blazer, MD, MSCI

Breakout Session # 3  
Irene Blanco, MD, MS

Breakout Session # 4  
Donald Thomas, MD, FACP, FACR, RhMSUS

---

3:50 – 4:00 PM

## Closing Remarks

**Rosalind Ramsey-Goldman, MD, DrPH**  
ACR, COIN Chair  
Gallagher Research Professor of Rheumatology  
Northwestern University Feinberg School of Medicine

# TABLE OF CONTENTS

# SPEAKER BIOGRAPHIES

Allen Anandarajah, MD, MS . . . . .	9
Richardae Araojo, PharmD, MS . . . . .	9
Sergio Arce, MD, PhD . . . . .	10
Irene Blanco, MD, MS . . . . .	10
Ashira D. Blazer, MD, MSCI . . . . .	11
Jodi Bridge, Hons.B.Sc. . . . .	11
Joy Buie, PhD, MSCR, RN . . . . .	12
Charmayne Marie Dunlop-Thomas, MS, MPH. . . . .	12
Candace Feldman, MD, MPH, ScD. . . . .	13
Christele Felix . . . . .	13
Monique Gore-Massy . . . . .	14
Sarfaraz A. Hasni, MD, M.Sc. . . . .	15
Coby Hobar, MD. . . . .	15
Kenneth Kalunian, MD . . . . .	16
Stacey Kennedy- Conner, MAC . . . . .	16
Aleta McLean, LPC . . . . .	17
Pamela Payne Foster, MD, MPH. . . . .	17
Rosalind Ramsey-Goldman, MD, DrPH . . . . .	18
Saira Z Sheikh, MD . . . . .	18
Donald Thomas, MD, FACP, FACR . . . . .	19
Douglas White, MD, PhD . . . . .	19





## Allen Anandarajah, MD, MS

University of Rochester Medical Center



allen\_anandarajah@urmc.rochester.edu

I am a professor of medicine at the University of Rochester Medical Center. I currently am the associate chair for wellness in the department of medicine and previously was the clinical director for the division of Allergy, Immunology and Rheumatology.

My work in the area of healthcare disparities has led me to be part of the ACR's MIMICT project and currently the TIMELY project, both of which aim to increase minority participation in lupus clinical trials. Locally, I also started a program called IQ-LUPUS that looks into catering for the social needs of high-need, high-cost lupus patients in the Rochester area.

In addition to being a clinician and an educator, I have been able to secure funding for the above projects and also secured funding to develop educational programs for patients with rheumatoid arthritis. Additionally, I recently started a program called RA CHAMP. The latter aims to improve quality of life measures in patients with RA by taking a holistic approach to their care.



## Richardae Araojo, PharmD, MS

U.S. Food and Drug Administration

Rear Admiral Richardae Araojo serves as the Associate Commissioner for Minority Health and Director of the Office of Minority Health and Health Equity at the U.S. Food and Drug Administration (FDA). In this role, RDML Araojo provides leadership, oversight, and direction on minority health and health disparity matters for the Agency. RDML Araojo previously served as the Director of the Office of Medical Policy Initiatives in FDA's Center for Drug Evaluation and Research (CDER), where she led a variety of broad-based medical and clinical policy initiatives to improve the science and efficiency of clinical trials and enhance professional and patient labeling. RDML Araojo joined FDA in 2003, where she held several positions in CDER. RDML Araojo received her Doctor of Pharmacy Degree from Virginia Commonwealth University, completed a Pharmacy Practice Residency at University of Maryland, and earned a Master's degree in Pharmacy Regulation and Policy from the University of Florida.



## Sergio Arce, MD, PhD

**RemeGen Biosciences, Inc.**



sergio.arce@remegenbio.com

Sergio brings to RemeGen extensive experience as a basic and clinical Rheumatologist, as a researcher and entrepreneur, and as a widely published author and reviewer of medical and scientific publications. He studied at the Havana's Higher Institute of Medical Sciences, and National Institute of Nephrology in Cuba, and subsequently completed a doctoral dissertation on HLA compatibility and the receptor's immune response, which studied 1,700 primary kidney transplants. Sergio completed his postdoctoral studies with the prestigious German Rheumatism Research Center (DRFZ), and Charite University Medicine in Berlin, and with the Department of Microbiology and Immunology at the State University of New York at Buffalo.

Prior to joining RemeGen, Sergio was an Associate Medical Director with the GI Therapeutic Area Unit (Clinical Sciences) at Takeda -where he was involved in Clinical Trials aimed at evaluating the efficacy/safety of mAb used for the treatment of IBD-, Associate Professor in the Department of Biomedical Sciences, University of South Carolina School of Medicine Greenville, Adjunct Associate Professor at Prisma Health Cancer Institute, and Assistant Professor in the Departments of Internal Medicine, Division of Pulmonary Critical Care and Sleep Medicine at Brody School of Medicine. Concurrently, Dr. Arce was an Associate Member of the Witebsky Center for Microbial Pathogenesis and Immunology, Department of Microbiology and Immunology at the State University of New York at Buffalo, and Adjunct Assistant Professor in the Department of Microbiology and Immunology, also at Brody.



## Irene Blanco, MD, MS

**Northwestern University-Feinberg School of Medicine**



Irene.blanco@northwestern.edu

Irene Blanco, M.D., M.S., is a Professor in the Department of Medicine-Rheumatology and is the co-Director for the Clinical Research Ethics and Equity Consultative Service (CREEC) -- part of Northwestern University's Clinical and Translational Sciences (NUCATS) Institute. Through CREEC, she and her collaborators provide multidisciplinary consultative services to clinical investigators throughout the Northwestern Medicine and Lurie Children's health systems. CREEC focuses on ways to help investigators and IRBs address issues of equity in the design, execution and reporting of clinical trials. She is also working with NUCATS to develop research coordinator pathways and career development programs targeting under-represented students within local Chicago and Minority-Serving Institutions.

In addition, Dr. Blanco's particular research interests focus on addressing health disparities and the social determinants of health in rheumatology. She is also currently working on developing medical education curriculum addressing disparities and health equity in Rheumatology.



## Ashira D. Blazer, MD, MSCI

Hospital for Special Surgery

 blazera@hss.edu

Dr. Ashira Blazer is an Assistant Professor of Rheumatology at Hospital for Special Surgery, who studies the biologic and genetic determinants of lupus severity in patients of African ancestry. She has forged multiple international collaborations with rheumatology programs in West Africa, spearheading the development of unique bio registries in Accra, Ghana, and Lagos, Nigeria. Dr. Blazer has received several funded grants through the Rheumatology Research Foundation, International League of Associations for Rheumatology (ILAR), Lupus Research Alliance, and the National Institutes of Health. She was most recently awarded a K23 research development award from NIAID to continue her work on APOL1 regulation and expression in lupus at HSS. Furthermore, Dr. Blazer is committed to mentorship and education and is working to advance diversity, equity, and inclusion in the field of Rheumatology in part through her role as the co-chair and inaugural member of the American College of Rheumatology DEI subcommittee. In recognition of her work as a thought leader in reducing health disparities, she was appointed as a 2020 National Minority Quality Forum 40 under 40 leader in Minority Health.



## Jodi Bridge, Hons.B.Sc

Roche/Genentech

 jodi.bridge@roche.com

Ms. Bridge holds a specialized honours degree in Biomedical Toxicology from the University of Guelph in Ontario, Canada. She is a Senior Clinical Operations Leader with over 20 years' experience in industry spanning central lab, CRO and pharma. She is currently overseeing the Operations of multiple studies in lupus nephritis, SLE and other nephrology and rheumatology indications at Roche/Genentech. In addition to her role in clinical trial execution, she acts as a D&I Strategist and has experience devising D&I recruitment and retention plans, establishing external patient, KOL and vendor partnerships in the discipline and bringing D&I solutions to study teams.



## Joy Buie, PhD, MSCR, RN

Lupus Foundation of America

 [buie@lupus.org](mailto:buie@lupus.org)

Dr. Joy Buie is a translational immunologist and health disparities researcher with a career spanning 14 years. Currently serving as the Director of Research at the Lupus Foundation of America, she has made notable strides in addressing racial and ethnic disparities in disease outcomes.

Early in her career, her interest in the role of epigenetics in vascular remodeling led to her involvement in the American Heart Association's Strategically Funded Research Network. There, she addressed disparities in stroke outcomes by creating culturally congruent workflows. These pioneering strategies ensured continuous engagement with acute stroke patients, significantly improving treatment outcomes.

Currently, Dr. Buie plays a pivotal role in the Improving Minority Participation and Awareness in Clinical Trials (IMPACT+) project funded by the Office of Minority Health. This initiative emphasizes nurse, lupus patient, and patient navigator education, focusing on enhancing communication about clinical trials with African American women living with lupus. Her work is integral in addressing access challenges and highlighting the parallels that exist in both clinical care and clinical trials.

Dr. Buie earned her Ph.D. from the Medical University of South Carolina, and also holds a Master's in Clinical Research and Bachelor's in Nursing. Her dedication to addressing health disparities, backed by her professional and personal experiences, provides her with a unique perspective in shaping strategies to bridge clinical trial participation gaps in minority communities living with lupus. Her commitment to equality in healthcare remains an inspiration to her peers and a beacon of hope to the communities she serves.



## Charmayne Marie Dunlop-Thomas, MS, MPH

Emory University School of Medicine

 [cmdunlo@emory.edu](mailto:cmdunlo@emory.edu)

Charmayne is an Associate Director of Research Projects in the Division of Rheumatology at Emory University School of Medicine. Her academic experiences are grounded in both psychology and public health. She is a graduate of Emory University College (BA), Georgia State University (MS), and Emory University Rollins School of Public Health (MPH).

Charmayne has over 25 years of research experience, including establishing and maintaining study-patient rapport and collaborations with agencies, organizations, and community partners. She has worked with Dr. Sam Lim since 2008, developing and managing the operational, recruitment, and data collection activities and teams associated with the Georgians Organized Against Lupus (GOAL) cohort. Her primary research interests include studies of the psychosocial impact on health-related outcomes. She has co-authored one book chapter and 15 publications and orally presented four studies at the American College of Rheumatology and Caribbean Exploratory Research Center health disparities conferences. She especially enjoys opportunities to use research findings to develop and implement support approaches and programs for people with lupus.

Charmayne is an avid learner who embraces opportunities to engage and connect with people. She is a US Virgin Islander and enjoys the outdoors especially swimming, running, and gardening.





## Candace Feldman, MD, MPH, ScD

Brigham and Women's Hospital and Harvard Medical School



cfeldman@bwh.harvard.edu

Candace Feldman, MD, MPH, ScD is an Assistant Professor of Medicine at Brigham and Women's Hospital and Harvard Medical School in the Division of Rheumatology, Inflammation and Immunity. Clinically, she is a practicing rheumatologist with a specific focus on the care of patients with lupus as well as patients with complex medical and social needs. Her research focuses on racial, ethnic and socioeconomic health disparities in rheumatic diseases and intervention design to reduce disparities in avoidable outcomes and trial participation. She is the Co-Director of Health Equity Initiatives for the BWH Department of Medicine and leads Diversity, Equity and Inclusion Efforts for the Division of Rheumatology. Her current research is supported by grants from the NIH, the Bristol Myers Squibb Foundation and the Arthritis Foundation to study social determinants of health and equity-related issues in rheumatology and musculoskeletal diseases



## Christele Felix

LupusChat



cfelix@lupuschat.org

My name is Christele Felix and I became a Lupus advocate by default when I was diagnosed in April 2007. My Lupus diagnosis and the impact of its symptoms threatened but thankfully did not end my college career. I have a background in Biological Science and a strong interest in Clinical Research. As an advocate, I've worked with doctors, data analysts, researchers, and patients to ensure that the patient voice is represented in healthcare and research. I am a COO and co-host of LupusChat, a patient led empowerment and advocacy community, whose goal is to educate patients, healthcare professionals, politicians, community leaders and the general public about Lupus and about the need for more research and better treatment for Lupus patients.

I have thrice presented research posters at the American College of Rheumatology annual meeting and serve as a consumer reviewer for the Congressionally Directed Medical Research Programs's Lupus Research Programs. Additionally, I am part of the inaugural PALS (Patient Advocates for Lupus Studies) program, a Lupus


Therapeutics initiative, where I educate patients about the clinical research process with the goal of improving clinical trial enrollment, especially for Black patients and patients of color. I also serve on multiple advisory boards, offering insight to researchers and pharma on clinical trial design, and I am involved with LFA, LRA, and LADA's efforts to improve clinical trials.





## Monique Gore-Massy

**Global Lupus Patient Advocate/ National Ambassador  
& DEI Champion/ Minister**

 iamgoldenmoe@hotmail.com

Monique is a distinguished and awarded Global Lupus Advocate, Diversity Equity & Inclusion Champion, Patient Experience Researcher & Patient Opinion Leader Consultant, Motivational Speaker, Writer, and Strategist. She's Co-Chair of the patient board & steering committee member for the *COVID-19 Global Rheumatology Alliance* - a division of the American College of Rheumatology, Lupus Foundation of America - Ambassador & Lupus Research Action Network Member, *Lupus Research Alliance* – Multi-Cultural Task Force Member, WEBMd -Patient Contributor, Freelance Blogger, appointed member of multiple acclaimed Pharma Patient Advisory Boards, mentor, and campaign/ civic leader for Dem reps like Sen. Parker (BK, NY), Cory Booker (NJ) Rep. Mikie Sherill (NJ). She bridges her former career in financial services and HR Recruiter through volunteering with orgs like the *National Assoc of Professional Women, Dress for Success, and NAACP*. She's an equity-driven leader connecting and empowering disparate narratives, the gospel is her compass.

Monique's features range from Robin Roberts, LifeTime TV – Access Health, Hollywood Health, People Magazine, Women's Health Magazine, NBC, Time Warner Media, PharmaVoice, Reuters Pharma, presenting to Foreign Ministers, US Capitol Hill, etc. Most recently in March 2023, Monique was honored for her "Leadership in Advocacy" by the *Autoimmune Association*. A common thread that runs through all of her endeavors, is being a messenger of God's love and hope.

Monique utilizes her perspective as a sought-after thought leader in patient engagement and DEI. She collaborates with patients, care-partners, and interdisciplinary teams in industry, media, legislative government, etc. - advising on the importance diverse, inclusive, and equitable patient centricity in transformative policies and care delivery. She participates in innovative research and quality initiatives to promote lupus awareness, amplifying the patient voice, identify/address patient outcomes, health disparities, health literacy, health equity, shared-decision making, mental health, and holistic wellness; particularly with autoimmune diseases. Monique caucus' with other groups across health disciplines to improve patient access and research funding. She spearheads actionable strategies that center and edify the whole individual.

Monique's ongoing journey has fueled her passion, and curiosity to serve and fortify others. As LemonadeMaker, she's intentionally making lemonade from life's lemons, nothing is lost, She gratefully strives to stir up possibilities and pass the baton forward, so *ALL* persons can be found in the room where it happens". Minister, Wife, Mom, and Pawrent to Mr Chip.



## Sarfaraz A. Hasni, MD, M.Sc.

**National Institutes of Health**



Sarfaraz.Hasni@nih.gov

Sarfaraz Hasni is the Director of Lupus Clinical Research at the National Institute of Arthritis, Musculoskeletal, and Skin Diseases (NIAMS) of the National Institutes of Health (NIH) in Bethesda, Maryland, USA. He did his post-graduate training in Internal Medicine and Rheumatology from State University of New York at Stony Brook and a Master of Health Sciences in Clinical Research from Duke University. He is the recipient of William G. Coleman Minority Health and Health Disparities Research Innovation Award for his study to increase participation in clinical research using a peer-peer approach in lupus patients from underrepresented minorities. He has established DC lupus consortium, a platform to bring together physicians, patients, and patient advocates to brainstorm ideas about improving lives of lupus patients through clinical research. He has partnered with the National Minority Quality Forum's Center for Sustainable Health Care and The Faith Health Alliance (a group of 20 Black Churches across the nation) to promote participation in clinical research among Black individuals with Lupus. He serves as chair of the scientific review committee for the US Department of Defense, Congressionally Directed Medical Research Programs, and scientific reviewer for the NIH-IRB. Dr. Hasni has been invited to present his research at multiple regional, national, and international conferences, medical grand rounds, patient summits, and keynote lectures.



## Coby Hobar, MD

**Bristol Myers Squibb**



Coby.Hobar@bms.com

Coby serves as a Clinical Development Lead in Immunology Global Drug Development at Bristol Myers Squibb. Since joining BMS in 2020, her focus has been on clinical research in systemic and cutaneous lupus. Prior to becoming an employee of BMS, she worked as a therapeutic expert on multiple systemic lupus and lupus nephritis trials for a CRO and served as a core member of the deucravacitinib PAISLEY study team. She completed her Rheumatology training at the University of Tennessee in Memphis where she served as sub-investigator on clinical trials in LN and osteoporosis before joining a multi-specialty group in Florida to treat patients with lupus and other autoimmune conditions.



## Kenneth Kalunian, MD

### UC San Diego School of Medicine

Kenneth Kalunian, MD, is a board-certified internal medicine physician who specializes in treating lupus, rheumatoid arthritis, osteoarthritis, dermatomyositis, gout and pseudogout and other rheumatic diseases.

A professor in the Division of Rheumatology, Allergy and Immunology at UC San Diego School of Medicine, he is actively working to develop new treatments for arthritis and inflammatory disease. He is also interested in developing ways to predict patient response to treatment for arthritis and other rheumatic diseases.

He is associate director of the Center for Innovative Therapy, director of the Osteoarthritis Center and director of the Lupus Clinical Trials Consortium, all at UC San Diego School of Medicine

Prior to joining UC San Diego Health in 2003, he was a professor of medicine at the David Geffen School of Medicine at UCLA.

Dr. Kalunian completed fellowship training in arthroscopic surgery at Lutheran General Hospital in Chicago. He completed fellowship training in rheumatology and residency training in rheumatology at the David Geffen School of Medicine at UCLA. He earned his medical degree at Saint Louis University, School of Medicine.

Dr. Kalunian is a fellow of the American College of Rheumatology. He is board certified in internal medicine.



## Stacey Kennedy-Conner, MAC

### Lupus Therapeutics



kennedy.stacey24@gmail.com

Stacey Kennedy-Conner is a 20 year warrior of Systemic Lupus Erythematosus (SLE)! Stacey has become a strong advocate in Lupus healthcare, research- specifically clinical trials, and patient engagement.

Stacey holds a Bachelor's Degree in Psychology from the University of Chicago and a Master's Degree in Counseling from Adler University. Both degrees have truly assisted Stacey in her work as a volunteer with various Lupus organizations and as a peer support leader.

Currently Stacey is the President of the Associate Board of Lupus Society of Illinois. The board aims to host social events and provide awareness to Lupus patients via workshops, walks, conferences, and a variety of other events.

Stacey is also a Patient Advocate for Lupus Studies ( PALS) with Lupus Therapeutics educating other individuals living with Lupus on clinical trials and the importance of participation.

Stacey has participated in various clinical trials, focus groups, and speaks on occasions to organizations like Antidote, LUCIN, and many community health events around the importance of Lupus research and clinical trials. All with an emphasis on increasing the diversity of participants in clinical trials. Lastly, Stacey was so moved by a clinical study she was a part of called Lupus Conversations that she continues to go into minority communities to have conversations about lupus, advocacy and increasing the sample size of minority participating in trials.

Stacey is absolutely committed to the work being done in Lupus research and healthcare. The goal is and will always be about setting the bar high, pushing the limits, educating and advocating for and with Lupus patients and those who support the cause.



## Aleta McLean, LPC

Open Hand Atlanta, Inc.



amclean@projectopenhand.org

Aleta McLean is a Licensed Professional Counselor, with a Masters in Professional Counseling from Argosy University, and a Bachelor of Science in Community Health Education from Clark-Atlanta University. She is currently the Senior Director of Client Services and Outcomes Tracking for the nonprofit Open Hand Atlanta where she has been employed the last 18 years. She directs Client Services team members who work to ensure that services are coordinated with multiple community partners and providers, and that clients are satisfied with services received. Aleta has been a driving force in Open Hand becoming a preferred provider of partner-agencies. Aleta also manages the Programmatic Team which leads programs and policy, processes, and evaluation of outcomes, oversees government grants and the community Registered Dietitian Nutritionists.

Aleta currently serves as the advocacy co-chair and a support group leader for the Lupus Foundation of America, Georgia chapter. She has worked as a patient advocate and clinical trial recruitment consultant for Lupus studies programs for various organizations.



## Pamela Payne Foster, MD, MPH

University of Alabama - Tuscaloosa



pfoster@ua.edu

Dr. Pamela Payne Foster is a Preventive Medicine/Public Health physician who currently serves as Professor in the Community and Rural Department at the University of Alabama School of Medicine, Tuscaloosa campus as well as Deputy Director for Outreach in the Institute for Rural Health Research. Dr. Foster's current research area of interest is the study of HIV/AIDS related stigma in rural African Americans in Alabama, particularly in faith-based settings in rural Alabama as well as other health equity issues including increasing Blacks in clinical trials, diversity, equity and inclusion issues in artificial intelligence/machine learning and community engagement/bioethics in healthcare. Dr. Foster serves on several local, state and national nonprofit Boards including leadership positions around social justice and health equity issues. She and her husband, William Foster Jr founded a nonprofit AframSouth Inc where they also have a community radio station WUMO 94.5 FM in Montgomery, Alabama.


Dr. Foster received her BS degree in Chemistry Pre-Medicine from Xavier University in Louisiana and her MS in Biomedical Sciences and MD from Meharry Medical College in Nashville, Tennessee. She completed an Internship in Internal Medicine and Residency in Preventive Medicine/Public Health at State University of New York at Stony Brook where she also completed her MPH at Columbia University. She has served on the faculty of a variety of institutions including Morehouse School of Medicine, George Washington University, SUNY Stony Brook, and the National Bioethics Center for Health Care and Research at Tuskegee University.





## Rosalind Ramsey-Goldman, MD, DrPH

Northwestern University Feinberg School of Medicine


 rgramsey@northwestern.edu

Dr. Rosalind Ramsey-Goldman is the current Chair of the Collaborative Initiatives Special Committee for the American College of Rheumatology. She is the Gallagher Research Professor of Rheumatology at Northwestern University Feinberg School of Medicine (NUFSM) and an attending physician for Northwestern Medicine. She is the director of the Patient-Oriented Clinical Research Program in lupus with continuous funding from NIH, foundations, philanthropy, and industry since 1991 when she joined the faculty at NUFMS. Her research program examines risk factors to minimize complications in lupus including pregnancy, osteoporosis, malignancy, renal, and cardiovascular disease. Through national and international collaborations, she studies genetic risk factors for disease severity/susceptibility; collaborates on investigations studying pathogenesis of disease; develops disease classification criteria, flare assessments, nephritis guidelines, disease impact (damage and frailty), assessment of patient-reported outcomes (including an investigator-initiated NIAMS/NIH funded clinical trial testing an intervention to mitigate fatigue, a pervasive problem affecting 90% of patients with lupus), and developed computable phenotype tools to detect SLE patients in the electronic medical record. Many of these clinical investigations incorporate analysis of lupus in multiethnic cohorts examining clinical, laboratory, and health related outcomes. An underlying theme for these investigations is a longstanding interest in documenting health disparities in lupus and experience working in community-academic partnerships.



## Saira Z Sheikh, MD

University of North Carolina at Chapel Hill

 szsheikh@email.unc.edu

Dr. Saira Sheikh is the Linda Coley Sewell Distinguished Professor of Medicine at UNC. She is a nationally renowned physician, researcher, and educator. She is trained, and triple board certified in Internal Medicine, Rheumatology and Allergy/Immunology. She is the Director of the Clinical Trials Program at the UNC Thurston Arthritis Research Center, as well as the UNC Rheumatology Lupus Clinic. Her work focuses on answering scientific questions that directly impact the care of patients with complex immunologic diseases, such as Systemic Lupus Erythematosus. She is Principal Investigator on numerous clinical trials for new therapeutics. She is leading national initiatives to develop real-world, practical models to promote inclusion of racially and ethnically diverse patients in lupus clinical trials.

Dr. Sheikh is the Vice-Chair of the Lupus Clinical Investigators Network (LuCIN), which is largest lupus clinical trials network of academic centers in the United States and Canada. She completed a 3-year term on the American College of Rheumatology's Annual Meeting Planning Committee and has served as Co-Chair of the ACR's Annual Review Course. She also serves on the ACR's Board of Directors and is the ACR Board Liaison to COIN (Collaborative Initiatives).

Dr. Sheikh is a Fellow of the American Academy of Allergy, Asthma & Immunology (FAAAAI), the American College of Allergy, Asthma & Immunology (FACAAI), the American College of Rheumatology (ACR) and the American Society of Nephrology (ASN). She also serves on the Medical-Scientific Advisory Council for the Lupus Foundation of America and serves on the NIH/NIAMS Lupus Federal Working Group.





## Donald Thomas, MD, FACP, FACR

**Arthritis and Pain Associates of Prince George's County**



donthomasj@proton.me

Dr Thomas is in private practice specializing in caring for lupus patients in Greenbelt, Maryland as a Clinical Associate Professor of Medicine at the Uniformed Services University, Bethesda, Maryland, and also teaches at Walter Reed National Military Medical Center.

He authored the Lupus Foundation's seal-approved book *The Lupus Encyclopedia* from Johns Hopkins Press. He runs a lupus educational blog and Face Book Page called "The Lupus Encyclopedia" with over 30,000 followers worldwide.

He is a chair emeritus of the Medical and Scientific Advisory Board of the Lupus Foundation MidAtlantic chapter, received the Lupus Foundation's Hero Award in 2016 from the MidAtlantic Chapter, was President of the Rheumatism Society of the District of Columbia in 2016, and is the recent past Chair of the National Board of Directors of the Sjögren's Foundation.



## Douglas White, MD, PhD

**Gundersen Health System/  
American College of Rheumatology**

Douglas White, MD, PhD earned his MD and PhD degrees from the University of Iowa, followed by residency training in Internal Medicine at Parkland Hospital (UT-Southwestern) and fellowship training in rheumatology at Barnes-Jewish Hospital (Washington University in St. Louis) all in the United States. His PhD focused on effector functions of CD8 T cells and post-doctoral training on herpesvirus interactions with the host immune system.

In 2009 he became the Chair of Rheumatology at Gundersen Health System in La Crosse, Wisconsin where he also served as head of the Rheumatology Research lab from 2009-2021. He is Clinical Adjunct Assistant Professor in the Department of Medicine at the University of Wisconsin School of Medicine and Public Health and President of the American College of Rheumatology where he has served in a number of roles since 2011. He serves on the board of directors of the Local Lupus Alliance in La Crosse, WI.

# RESOURCES

Engaging Diverse Participants  
in Lupus Clinical Trials:  
The Path Forward

AMERICAN COLLEGE  
of RHEUMATOLOGY  
*Empowering Rheumatology Professionals*

Resource Name	Resource Link
ACR Online Education Center – CME/MOC	<a href="https://learn.rheumatology.org/totara/dashboard/index.php">https://learn.rheumatology.org/totara/dashboard/index.php</a>
The Lupus Initiative (TLI) – Patient and Provider Resources	<a href="https://thelupusinitiative.org/">https://thelupusinitiative.org/</a>
Self-Management Tools for Living with Lupus	<a href="https://selfcare.thelupusinitiative.org/">https://selfcare.thelupusinitiative.org/</a>
Pregnancy and Lupus Resources	<a href="https://rheumatology.org/reproductive-health-initiative">https://rheumatology.org/reproductive-health-initiative</a>
The Lupus Initiative (TLI) Clinical Trial Search Tracker	<a href="https://thelupusinitiative.org/mimict-2/">https://thelupusinitiative.org/mimict-2/</a>
Use of Popular Opinion Leader Models to Disseminate Information About Clinical Trials to Black Individuals with Lupus in Two US Cities	<a href="https://onlinelibrary.wiley.com/doi/10.1002/acr.24889">https://onlinelibrary.wiley.com/doi/10.1002/acr.24889</a>
Using Critical Race Theory to Understand Trial Participation Among Black Individuals with Systemic Lupus Erythematosus: A Qualitative Study of Patients and Caregivers	<a href="https://onlinelibrary.wiley.com/doi/10.1002/acr.24635">https://onlinelibrary.wiley.com/doi/10.1002/acr.24635</a>
Factors Associated with Participation in Rheumatic Disease-Related Research Among Underrepresented Populations: A Qualitative Systematic Review	<a href="https://onlinelibrary.wiley.com/doi/10.1002/acr.24036">https://onlinelibrary.wiley.com/doi/10.1002/acr.24036</a>
Let's Take Charge! Campaign	<a href="https://www.minorityhealth.hhs.gov/letstakecharge/">https://www.minorityhealth.hhs.gov/letstakecharge/</a>
Lupus Clinical Trials Unit	<a href="https://www.niams.nih.gov/labs/hasni-lab#tab-overview">https://www.niams.nih.gov/labs/hasni-lab#tab-overview</a>
U.S. National Library of Medicine: Clinical Trials	<a href="https://www.clinicaltrials.gov/">https://www.clinicaltrials.gov/</a>
NIH Clinical Center Trials	<a href="https://clinicalstudies.info.nih.gov/">https://clinicalstudies.info.nih.gov/</a>
A Provider-Based Approach to Address Racial Disparities in Lupus Clinical Trial Participation	<a href="https://onlinelibrary.wiley.com/doi/full/10.1002/acr.25054">https://onlinelibrary.wiley.com/doi/full/10.1002/acr.25054</a>
EMBRACE: One Small Story in Lupus-One Giant Challenge in Clinical Trials	<a href="https://onlinelibrary.wiley.com/doi/10.1002/acr2.11477#">https://onlinelibrary.wiley.com/doi/10.1002/acr2.11477#</a>
The State of Lupus Clinical Trials: Minority Participation Needed	<a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6722692/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6722692/</a>



AMERICAN COLLEGE  
*of RHEUMATOLOGY*  
*Empowering Rheumatology Professionals*

For more information visit  
[www.rheumatology.org](http://www.rheumatology.org)