



CONFERENCE REPORT

**National Organization of African Americans
with Cystic Fibrosis (NOAACF)**

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EXECUTIVE SUMMARY

The National Organization of African Americans with Cystic Fibrosis (NOAACF) hosted the 1st Annual BIOMERGD (Blacks, Indigenous, and Other Minority Ethnicities with Rare and Genetic Diseases) Conference on Saturday, February 27, 2021, from 1:00 – 3:00 pm CST.

The BIOMERGD conference was sponsored and hosted by NOAACF and coincided with Rare Disease Week 2021 and took place the day before Rare Disease Day 2021.

There are more than 7,000 different rare diseases, collectively affecting more than 350 million people around the world (National Organization for Rare Disorders, NORD). Ethnic and racial minorities may also experience a higher incidence and prevalence of rare diseases than the general population for a variety of reasons, genetic and otherwise (National Institutes of Health, NIH). Indeed, racial and ethnic minorities and other underserved populations are likely to experience even greater barriers to screening, diagnosis, and treatment of rare diseases than for common conditions due to a variety of cultural, socioeconomic, and environmental factors.

NOAACF's BIOMERGD conference strives to increase awareness of rare diseases in the black, indigenous and people of color (BIPOC) communities by focusing on one genetic disease and one rare disease each year. The first conference focused on cystic fibrosis and systemic lupus erythematosus, which has impacted NOAACF co-founders Terry Wright and Michele Wright, respectfully.

ABOUT NOAACF

The National Organization of African Americans with Cystic Fibrosis (NOAACF) is a 501(c)(3) non-profit organization established in honor of Terry Wright, a 58-year old African American male Cystic Fibrosis (CF) patient who was not diagnosed until the age of 54, although he had been hospitalized, seen by an array of healthcare practitioners, and was unknowingly dealing with the devastating consequences of CF throughout his entire life.

The mission of NOAACF is to engage, educate, and raise CF awareness in the African-American community to help bring valuable resources, knowledge, empowerment, and support to CF patients, families, healthcare professionals, and the community.

Through widespread involvement, partnerships, and outreach, NOAACF's program scope is to ensure that the diverse Cystic Fibrosis community is educated, informed, and made aware of CF's existence, prevalence, and impact on underrepresented communities.

NOAACF's goals are to connect, engage, and raise CF Awareness in the African-American Community and beyond through its national platform.

If I can help make a difference and positively impact the life of just one Cystic Fibrosis patient, then my living, suffering, and CF journey will not have been in vain! ~ Terry G. Wright

NOAACF BOARD MEMBERS

BIOMERGD was sponsored by NOAACF and co-chaired by NOAACF Co-Founders, Terry Gene Wright and Michele Wright, Ph.D. and planned by the NOAACF Board Members, which consists of a diverse array of community influencers from across multiple unique platforms.



Top (L-R): Michele Wright, PhD (Co-Founder and Chairperson), Terry Gene Wright (Co-Founder and President), Beth Sufian, JD, and Amy Hester, PhD, RN, BC;
Bottom (L-R): Everett Rice (Secretary) and Zipporah Sealy, MSW

Terry Wright, NOAACF Co-Founder and President

Terry Gene Wright is the 58-year old president and co-founder of the National Organization of African Americans with Cystic Fibrosis (“NOAACF”). At the age of 54, Terry was unexpectedly diagnosed with cystic fibrosis. He shares his surreal journey to CF land in his children’s coloring storybook, “Terry’s Journey to CF Land,” which was listed in the top spot on BookAuthority’s “8 Best New Cystic Fibrosis Books To Read In 2021”. Terry is the winner of the CF Star Award for 2020 presented by the Cystic Fibrosis Foundation – Arkansas Chapter and the 2020 Jacoby Angel Award, the highest award presented by the U.S. Adult Cystic Fibrosis Foundation (“USACFA”).

Michele Wright, PhD, NOAACF Co-Founder and Board Chair

Michele Wright, PhD is the 54-year old Co-Founder and Broad Chair of the National Organization of African Americans with Cystic Fibrosis (NOAACF). She was diagnosed with systemic lupus erythematosus 27 years ago on February 14, 1994. She is the recipient of the Nations of Women Change Makers 2021 Global Leadership Award. She is the CEO and Founder of My Water Buddy® and My Learning Buddy® corporations. Dr. Wright is the CEO and Founder of My Water Buddy®

and My Learning Buddy® corporations. She is the author and creator of THE WATER TALES: Ten Life Lessons from My Water Buddy and Family podcast and the children's book.

Beth Sufian, JD, NOACF Board Member

Beth Sufian, JD is Director of the CF Legal Information Hotline and Director of the CF Social Security Project. She has been practicing law for 30 years. Ms. Sufian is a partner in law firm of Sufian & Passamano, LLP and focuses her practice on representing individuals with chronic illness in matters related to Social Security benefits, health insurance, education and employment rights. Beth has helped thousands of people with cystic fibrosis obtain Social Security benefits and access to Medicaid and Medicare benefits. Beth spends most of her time representing individuals with cystic fibrosis around the country. Through the CF Legal Information Hotline Beth provides information to help people with CF, their family members and CF Care team members advocate for their rights. Beth has written 3 books on disability law.

Amy Hester, PhD, RN, BC, NOACF Board Member

Amy Hester, PhD, RN, BC is the Chairwoman and CEO of HD Nursing, a leading provider of patient safety solutions. Dr. Hester co-founded HD Nursing in 2012 along with her colleague Dees Davis to develop and enhance the science behind falls prevention. She previously served as HD Nursing's Chief Scientific Officer and was Director of Nursing Research and Innovation at the University of Arkansas for Medical Sciences (UAMS) before retiring after 26 years of service. Dr. Hester continues to serve as adjunct faculty for the UAMS College of Nursing and as clinician in residence for Health Tech Arkansas where she helps young startups get a footing in healthcare.

Everett Rice, NOACF Board Member and Secretary

Everett Rice is a Communications and Community Engagement Specialist with the California State Senate, where he advises and develops messaging and marketing for state Senators. He specializes in strategic messaging and branding, policy development and community and organizational empowerment. He has over 25 years of experience in California politics and political communication. Everett also lives with Cystic Fibrosis and CF-related Diabetes. He was diagnosed with cystic fibrosis at the age of 9 and at 50-years old lives with Cystic Fibrosis and CF-related Diabetes.

Zipporah Sealy, MSW, NOACF Board Member

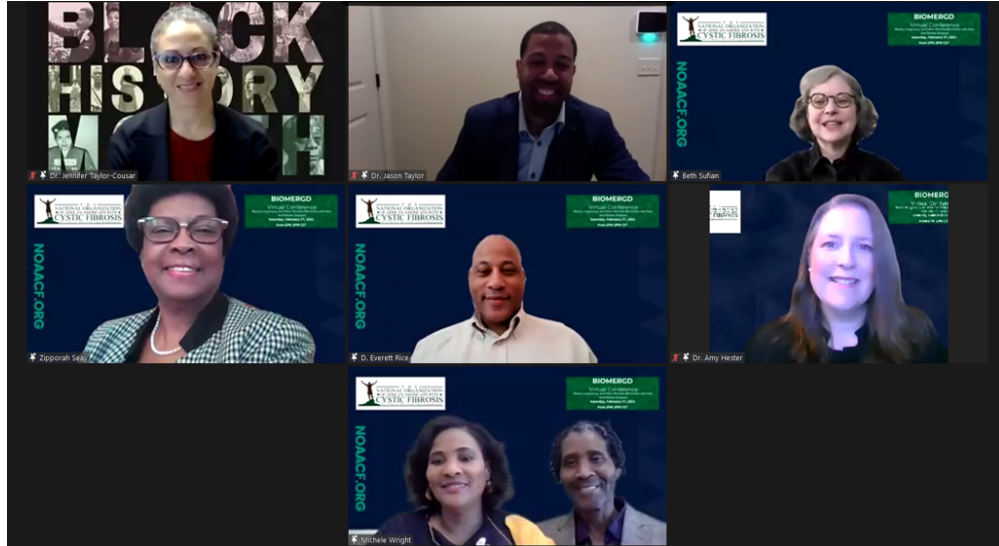
Zipporah Sealy, MSW is a social worker at the Cystic Fibrosis Center at St Christopher's Hospital for Children in Philadelphia, Pennsylvania. Prior to working at St Christopher's, she worked at Yale New Haven Hospital, New Haven, Connecticut and The Children's Hospital of Philadelphia. At Yale University Hospital, she pioneered the 'Sister to Sister' early cancer detection program which provided education and free mammograms to uninsured and underinsured women in New Haven, Connecticut. She likes people and enjoy helping them. It is in this arena that she does her best work. Her career and passion have been focused on working with underserved communities.



CONFERENCE AGENDA

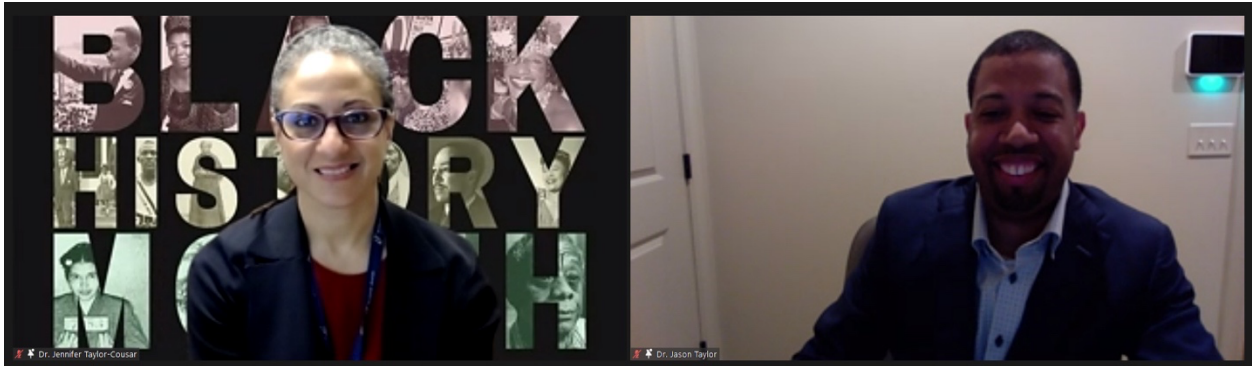
The two-hour conference agenda was as jam-packed with invaluable information as follows:

Welcome	Michele and Terry Wright
Introduction of Speaker #1	Beth Sufian, JD
CF Keynote Speaker/Q&A	Dr. Jennifer Taylor-Cousar, MD Future Directions in CF – No One Left Behind
Introduction of Speaker #2	Michele Wright, PhD
Lupus Keynote Speaker/Q&A	Dr. Jason Taylor, MD Lupus: Clinical Manifestations and Management
Expert Panel Segment	Moderator: Amy Hester, PhD, RN, BC <u>Panel of Experts:</u> <ul style="list-style-type: none"> • Terry Wright (58-year old Cystic Fibrosis Patient) • Michele Wright, PhD (54-year old Lupus Patient) • Everett Rice (50-year old Cystic Fibrosis Patient) • Zipporah Sealy, MSA (Social Worker and Healthcare Expert)
Closing/Words of Thanks	Michele and Terry Wright



KEYNOTE SPEAKERS

BIOMERGD featured two renowned speakers who are nationally respected leaders in their field – Dr. Jennifer Taylor-Cousar who spoke on cystic fibrosis and Dr. Jason Taylor who spoke on lupus.



Dr. Jennifer Taylor-Cousar, MD, MSCS
 Professor of Medicine and Pediatrics
 Great Strides and Future Directions in CF

Dr. Jason K. Taylor, MD
 Doctor of Internal Medicine and Rheumatology
 Lupus: Clinical Manifestations and Management

Dr. Jennifer Taylor-Cousar, MD, MSCF – CF Keynote Speaker (Bio/Slide Samples)

Dr. Jennifer L. Taylor-Cousar, MD, MSCS, is a pediatric and adult pulmonologist at National Jewish Health, Denver, CO, where she also serves as the Medical Director of Clinical Research Services; President-Elect for the Medical Staff; Co-Director of the Adult Cystic Fibrosis Program; Co-Director of the Adult Cystic Fibrosis Program; and the Cystic Fibrosis Therapeutics Development Director.

Dr. Taylor-Cousar has been site primary investigator on more than 45 clinical studies, and global site investigator on 3 clinical trials. She is an elected member of the American Society for Clinical Investigation (2020). Her investigator initiated research focuses on the development and evaluation of novel therapies for the treatment of CF, and on the unique health needs of women with CF. She is also investigating the etiology and treatment of bronchiectasis in non-human primates.

She serves on numerous local and national committees including the CF Foundation's Clinical Research Advisory Board, the CF TDN's Clinical Research Executive Committee and as Chair of the CF TDN's Women's Health Research Working Group. She recently completed service on the American Thoracic Society (ATS) Scientific Advisory Committee, and is the elected Chair for the 2020-2021 ATS Clinical Problems Programming Committee. She has co-chaired numerous sessions and given invited lectures at the ATS International Conference, and the North American, European and Australian CF Conferences, as well as at regional CF and pulmonary conferences and national and international veterinary conferences. She is an active member of the Colorado Chapter CF Board.

Dr. Taylor-Cousar is a tenured professor of adult and pediatric pulmonary medicine at National Jewish Health (NJH), where she serves as the Medical Director of Clinical Research Services, President-elect of the medical staff, and is co-director of the Adult CF Program and Director of the CF Therapeutics Development Network (TDN) center. She received her undergraduate degree in human biology from Stanford University in 1993, and completed her doctorate in medicine in 1998, combined residency in internal medicine and pediatrics in 2002, and her combined fellowship in adult and pediatric pulmonary medicine in 2006 at Duke University Medical Center. She obtained her Master of Clinical Science from the University of Colorado in 2015.

Great Strides and Future Directions in CF- No One Left Behind

Jennifer L. Taylor-Cousar, MD, MSCS, ATSF

Professor of Medicine and Pediatrics,

Divisions of Pulmonary, Critical Care and Sleep Medicine and Pediatric Pulmonary Medicine

Medical Director, Clinical Research Services

Co-Director and CF TDN Director, Adult CF Program

National Jewish Health

Professor of Medicine and Pediatrics,

Divisions of Pulmonary Sciences and Critical Care and Pediatric Pulmonary Medicine

University of Colorado Anschutz Medical Campus

BIOMERGD

February 2021

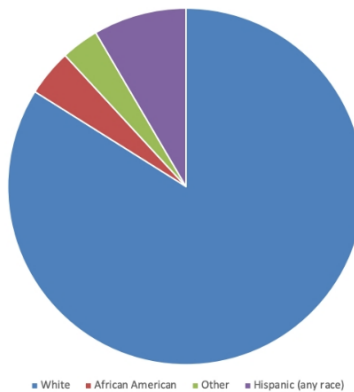


OUTLINE

- Cause, Diagnosis, Epidemiology and Manifestations of CF
- Treatment of CF
- Future of CF Therapy

Incidence of CF by Race and Ethnicity in the U.S.

Racial Demographics of U.S. CF Population
N=31,199



US CFPR 2019

Summary

- Quantity and quality of life has improved for PwCF
- Although CF is more common in people of Caucasian descent, it can occur in someone of any race
- Treating the basic CF defect with highly effective modulators approved for **~90% of people with CF**
- Research for therapies to treat the signs and symptoms of CF and the basic defect in everyone with CF is ongoing

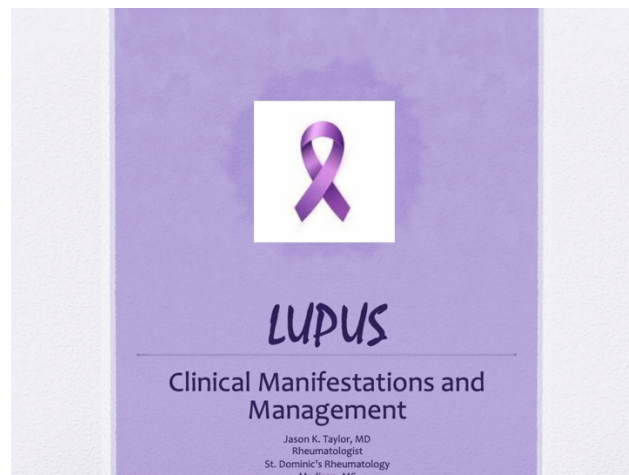


Dr. Jason Taylor, MD – Lupus Keynote Speaker (Bio/Slide Samples)

Dr. Jason K. Taylor, MD, is a nationally renowned and respected Rheumatologist and Internist. He is a native Mississippian and currently practices as a staff Rheumatologist at St. Dominic's Hospital located in Madison, MS. He received his undergraduate degree in Biology at Tougaloo College in 1999 and attained his medical degree from Saint Louis University School of Medicine in 2003. He completed both residency training in Internal Medicine in 2006 and fellowship training in Rheumatology in 2008 at the University of Mississippi Medical Center.

Dr. Taylor began his career in academics serving as an Assistant Professor of Medicine, Division of Rheumatology, at the University of Mississippi Medical Center and as a staff Rheumatologist at the G.V. Sonny Montgomery VA Medical Center. He has guest lectured at several local health-oriented symposiums, meetings, health affairs and awareness events and has previously served nationally on the American College of Rheumatology 2020 Task Force Committee as well as the Association of Rheumatology Health Professionals E-Learning Committee. He has been pivotal in reviving the state of Mississippi's Rheumatology Society, MSARS (Mississippi Arthritis and Rheumatism Society), by serving as President since 2016 where he has worked on promoting initiatives pertinent to the professional Rheumatology medical community.

Currently, Dr. Taylor is in private practice at St. Dominic's Hospital in Central Mississippi where he provides care for diverse diseases to include rare rheumatic diseases with a special interest in treating Lupus, Rheumatoid Arthritis, Scleroderma, and Osteoarthritis.



Objectives

- Epidemiology and Causes
- Manifestations
- Management

Epidemiology

- **Prevalence**
 - In the U.S: 20-150 cases per 100,000
- **Geographic and racial distribution**
 - More common in urban than rural areas
 - Higher prevalence among Asians, African-Americans, African Caribbeans, and Hispanic Americans compared to Caucasians

Epidemiology

- **Factors affecting disease outcome**
 - African-Americans frequently have more severe disease
 - Clinical status is poorer in those with less education, lower socioeconomic status and with inadequate access to medical care

Prognosis

- The 5 year survival rate in SLE has dramatically increased since the mid-20th century, from approximately 40% in the 1950s to greater than 90% since 1980s.

EXPERT PANEL DISCUSSION

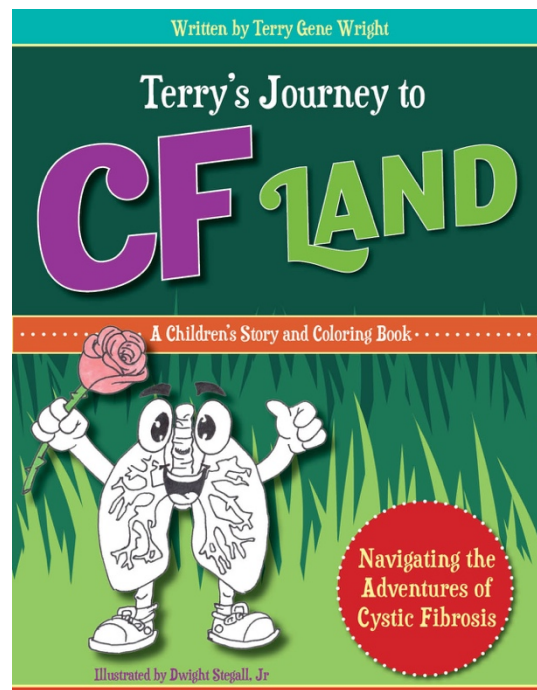
The Expert Panel was the final session of the 2021 BIOMERGD conference. It was moderated by NOAACF board member, Dr. Amy Hester, PhD, RN, BC, and made up of healthcare professionals and individuals with cystic fibrosis and lupus who will share their unique experiences, including: Terry Wright, NOAACF Co-Founder and President; Michele Wright, Ph.D., NOAACF Co-Founder and Board Chair; Everett Rice, NOAACF Board Member and Secretary; and Zipporah Sealy, MSW, NOAACF Board Member.

Panel questions included an array of intimate questions that focused on essential topics such as:

- Late and Delayed Diagnosis
- Issues experienced with being misdiagnosed for years
- Experience from a social work perspective
- How to advocate for patients who are seen experiencing health disparities
- How to advocate for one another with the various providers you see to be sure they understand you and your diagnoses?
- How can people self-advocate?
- How to you help colleagues with unconscious bias?

2022 BIOMERGD CONFERENCE

The 2022 BIOMERGD Conference took place on Saturday, February 26, 2022 and focused on Leukemia (Rare Disease) and Sickle Cell Disease (Genetic Disease). For more information, visit noaacf.org or email us at [noaacf.org](mailto:info@noaacf.org).



Announcing the
BIOMERGD

Virtual Conference

Blacks, Indigenous, and Other Minority Ethnicities with Rare
and Genetic Diseases

Saturday, February 27, 2021

from 1PM-3PM CST

Sponsored By:



Register Here:

https://us02web.zoom.us/webinar/register/WN_4fwYOirwQJShOiH0iE4KUw

Dr. Jennifer Taylor-Cousar, MD: Great Strides and
Future Directions in CF-No One Left Behind



Dr. Jason K. Taylor, MD: Lupus: Clinical Manifestations
and Management



NOAACF's mission is to engage, educate, and raise cystic fibrosis (CF) awareness in the African American community to help bring valuable resources, knowledge, empowerment, and support to CF patients, families, healthcare professionals, and the community.

For more information, visit us at:

www.noaacf.org