









African Americans and Clinical Trials: A Path Forward

The Launching of the National Black Church Initiative National Clinical Trial Strategic Plan (NCTSP)

FDA Fumbles With Its Diversity and Clinical Trial Policy

NBCI Launches Its Historic Clinical Trial Initiative

Who is ACHDC?

National Academy of Science Recommendations

Dr. David Satcher "More African Americans Need to Participate in Clinical Trials

SAMBAI: Dr. Melissa Davis

Salute to Dr. Richard Allen Williams

NBCI Clinical Trials Lecture Tour



Rev. Anthony Evans President, National Black Church Initiative



Dr. Joseph Webster Chair of ACHDC



Dr. James McCoy Co-Chair of ACHDC



NBCI AND ACHDC ARE USHERING IN A NEW ERA OF BROADENED ENGAGEMENT OF AFRICAN-AMERICAN AND LATINO COMMUNITIES IN CLINICAL TRIALS. PARTICULARLY GIVEN THE UNETHICAL AND ILLEGAL BEHAVIORS INVOLVED WITH THE TUSKEGEE EXPERIMENT AND THE INTENTIONAL ABSENCE OR LACK OF CRITICAL INFORMATION FOR THE INVOLVED SUBJECTS BY GOVERNMENTAL OFFICIALS, NBCI ENGAGES IN A COMPREHENSIVE APPROACH TO UTILIZE IM-PORTANT LESSONS LEARNED FROM HISTORIC MEDICAL ABUSES FOR GENERATING ROBUST INTEREST IN SUBSTANTIALLY IMPROVING CLINICAL TRIAL PARTICIPATION AND HEALTH OUTCOMES.

NBCI AND ACHDC CLINICAL APPROACH TO CARE 7 Evidence-Based Approaches for Improving Black Health Moving Toward A National Black Health Agenda Education Health Prevention / Health Promotion Disease Management Through Best Practices Promotion and Encouragement of Clinical Trials Understanding its Risks and Benefits Collection of Critical Data to Improve Care of NBCI 27.7 Million Members Creating Access To Care-Building a Roadmap for our Members Publication of Scientific Findings

View full size image at blackchurchclinicaltrials.com/img/nbci-updatefi-

National Black Church Initiative COMMUNITY SERVICE DELIVERY PROGRAM STRUCTURE Moving Toward a National Black Health Agenda ACHDC **NE** New York Cit MW c **Health Workers NBCI Congregational** NBCI Congregational Volunteer Health

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THERAPEUTIC AREAS OF INTEREST TO THE AFRICAN-AMERICAN AND LATINO COMMUNITIES: NBCI CLINICAL RESEARCH APPROACH

THERE ARE ELEVEN (11) PILLARS OF NBCI **CLINICAL RESEARCH APPROACHES TO BE USED:**

- Cardiovascular Diseases
- Cancer: (Liver/ Kidney/ Lung ...etc)
- Diabetes
- **Blood Diseases**
- Genetic Disease (Sickle Cell)
- Mental health 6.
- Access to Care/lifestyles/Selfcare
- Parkinson Disease 8.
- 9. Collection of Health Data
- 10. Alzheimer's Disease

"WE NEED TO FIND OUT WHETHER OR NOT THE MEDICINE WORKS ON AFRICAN AMERICANS AND LATINOS. THIS IS THE SOLE REASON WE MUST INCREASE OUR PARTICIPATION IN CLINICAL TRIALS!"



Dr. Joseph Webster Chair of ACHDC



Dr. James McCov Co-Chair of ACHDC

THE FDA HAS INTENTIONALLY UNDERMINED AND FUMBLED ITS DIVERSITY ACTION PLANS TO IMPROVE ENROLLMENT OF PARTICI-PANTS FOR UNDERREPRESENTED POPULATIONS IN CLINICAL STUDIES POLICY

NBCI encourages FDA to stay the course on Diversity Action Plans to Improve Enrollment of Participants from Underrepresented Populations in Clinical Studies policy. NBCI will not be deterred. We will continue to work with the FDA to respect and adhere to the scientific benefits of diversity in clinical trials that their research has verified.

The scripture teaches us never to give up the truth and always fight for it.

2 Corinthians 4:17-18 "Our light affliction, which is but for a moment, is working for us a far exceeding and eternal weight of glory" **1 Corinthians 10:13** "God is faithful, who will not allow you to be tempted beyond what you are able" **Galatians 6:9** "And let us not grow weary of doing good, for in due season we will reap, if we do not give up" **Ecclesiastes 3:1** "There is a time for everything and a season for every activity under the heaven"

HOW TO ENROLL IN A CLINICAL TRIAL

https://blackchurchclinicaltrials.com/participate.php

HOW YOUR COMPANY CAN ADVERTISE YOUR CLINICAL TRIAL TO THE AFRICAN AMERICAN COMMUNITY

https://blackchurchclinicaltrials.com/participate-form.php

NBCI LAUNCHES THE NATIONAL CLINICAL TRIAL STRATEGIC PLAN (NCTSP) THROUGH 150,000 AFRICAN AMERICAN CHURCHES

The health equity gap in the US is so vast that you could refer to it as a chasm. Marginalized groups, especially African Americans and Latinos, have worse outcomes with various health conditions, and worse, when it comes to clinical research to treat and prevent, these groups are grossly underrepresented. Closing that gap has taken greateffort, and the Black church has stepped up and taken the lead. The National Black Church Initiative National Clinical Trials Strategic Plan (NCTSP) (https:// naltblackchurch.com/pdf/nbci-ntcsp-slides3. pdf) has mirrored the call by the National Academies report on Improving Representation in Clinical Trials and Research, and the organization urges the FDA to use it as a blueprint.

The National Black Church Initiative (NBCI) (https://naltblackchurch.com), a coalition of 150,000 African American and Latino churches, has established a program to help close that gap. NBCI, representing 27.7 million members, is dedicated to eliminating racial disparities in healthcare, technology, education, housing, and the environment.

This program is in keeping with NBCI National Black Health Agenda (https://naltblackchurch. <u>com/pdf/blackhealthagenda-congress.pdf</u>). This report was sent to Congress, spelling out the needs of African Americans before the 2024 election election. The report is our bellwether on Black health. Through the NBCI, the Black church has developed the most comprehensive program to educate, empower, recruit, and sustain maximum participation of African Americans—along with African American physicians—in clinical trials. This initiative, known as the American Clinical Health Disparities Commission (ACHDC) (https://achdc.net/), marks the first serious and holistic effort to build on past attempts that failed to engage the Black community effectively.

Given the ongoing healthcare crisis affecting African Americans, which has worsened over the past 400 years, as highlighted by NBCI in its 2024 report to the U.S. Congress, "Moving Toward a National Health Agenda", this initiative demands full support from both industry and government.

National studies consistently show that the Black church's faith-based, science-driven approach has the most potential for success, owing to its deep-rooted position within the Black community.

NBCI's mission is to deliver essential wellness information to its members, congregants, churches, and the broader public. NBCI employs innovative and impactful solutions to address persistent economic and social challenges by combining faith with

evidence-based health science. The organization seeks partnerships with key entities and officials committed to reducing racial inequalities in these critical areas. NBCI's programs are driven by credible data, scientifically supported strategies, and proven methods that produce measurable results.

With the help of health experts, NBCI has developed a seven-part approach for improving Black health, and a major one encourages participation in clinical trials. This approach educates on trials and the conditions that greatly impact Black and Latino communities. That education also includes evidence-based insight on preventing and managing certain conditions.

With that in mind, NBCI is trying to solve a decades-old problem. Why do African Americans refuse to participate in clinical trials?

The complicated and yet straightforward answer is the fraught relationship between the US healthcare system and the strides made at the detriment of people of color.

That is where the Black church comes in. The creation of the blackchurchclinicaltrials.com (https://blackchurchclinicaltrials.com/) website is an innovative and interactive tool that, alongside the seven-clinical approach, is exactly what is needed in the Black church toolkit to provide its 27.7 million members with the critical information necessary to make informed decisions about participating in clinical trials.

One example of the website's content is the NBCI Clinical Trials Education Awareness Interactive Booklet, which helps members understand the risks and benefits of clinical trials. This booklet is specifically designed for African Americans by African American educators who are familiar with their various learning styles and approaches, as outlined by the NBCI Literature Review Committee.

Historic Mistreatment

The most famous case of mistreatment is the Tuskegee syphilis study, which stripped Black men of informed consent and available treatment options. The mistreatment did not stop there, and from the 1950s to 1970's predominantly Black prisoners were experiment subjects for a renowned dermatologist who discovered tretinoin. Even centuries before, the country's earliest medical advances were achieved at the expense of enslaved people. For instance, J. Marion Sims, who has been dubbed the "father of gynecology," performed vaginal fistula surgeries on enslaved women without the use of anesthesia.

Further, the controversial treatment also extends to Native Americans and Latinos. In the 1970's, up to 42% of native women of childbearing age were sterilized. Also, in the 1950s, up to 1/3 of child-bearing-aged Puerto Rican women were sterilized and unknowingly used as test subjects for the development of modern birth control.

Fortunately, in modern times and with better government oversight, clinical trials have been crucial for developing weight loss drugs, treating various cancers, and in late 2023, finally developing an effective treatment for sickle cell anemia.

Treating many conditions is important for diverse representation, since some groups may face worse outcomes or have a complex presentation of the disease. Diversity helps to uncover social determinants of health, including barriers to treating and complying with care. Nonetheless, the distrust in clinical trials persists.

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The Role of the Black Church

The Black church has been a refuge for its community and has built trust with Black people through commonality and shared customs. NBCI comprises 150,000 Black and Latino churches with 27.7 million members.

The Black church has the duty of facilitating meaningful conversations around faith and starting conversations around the community's overall wellbeing. That's why Black churches have been effective in combating issues such as COVID-19 vaccine hesitancy. NBCI has also successfully distributed information to and educated over 50,000 congregants who might not otherwise participate in clinical trials.

Considering its impact, NBCI has taken on a more significant task of fighting for health equity through trial access. This is NBCI's solution: NBCI National Clinical Trial Strategic Plan (NCTSP). The NCTSP aims to promote an interdisciplinary collaboration involving the pharmaceutical industry, government, and public health organizations to boost African American enrollment in clinical trials significantly.

Additionally, the goal is to strengthen the roles of both NCTSP and ACHDC as trusted and effective partners while enhancing African Americans' awareness and understanding of

clinical research. This education can help to eliminate unethical practices through informed consent.

The NCTSP fits within the recommendations of NBCI and the American Clinical Health Disparities Commission (ACHDC), a task force comprising 42 African American physicians. The ACHDC's objective is to oversee the strategic plan, lending guidance, technical support, ethical clinical trial protocols, and standards for critical data collection, education, literature, video development, program management, and safety.

The seven-part approach, as outlined in the plan includes the following:

- 1. Health education
- 2. Disease prevention and health promotion
- 3. Establishing best practices for disease management
- 4. Explaining risks and benefits to encourage clinical trial participation
- 5. Critical data collection
- 6. Providing church members with access to care
- 7. Publication of scientific findings

Health Education

NBCI is educating the church through various modes of communication. The website currently offers modules and other online tools for congregants. NBCI even provides a glossary of common medical words that prospective participants may not understand. The website also maintains a database of up-to-date trials sorted by condition and the first-of-its-kind course on clinical trials.

To go even further, NBCI has plans to distribute a newsletter called CLINICALNEWS. It will be a single-sheet news briefing to inform low-income Black and Latino communities about clinical trials. It will provide essential information on the basics of clinical trials, including their benefits and risks, in simple language. This news brief will be distributed to 150,000 churches nationwide and shared through human and civil rights organizations. Additionally, it will be published on social media, included as a supplement in 274 Black newspapers, and shared with regional dailies targeting African-American and Latino communities.

Increasing education leads to more informed consent, which can boost confidence in those considering the risks and benefits of participating in clinical trials.

Disease Prevention and Health Promotion

These practices should be carried out with insight from health professionals and government agencies. That is why NBCI collaborates with the ACHDC to disseminate accurate health information, which is shared

through various channels, reaching congregants in whatever way best serves them. Along with this step is establishing best practices for disease management, which is evidence-based and also overseen by physicians and qualified health professionals.

NBCI will also appoint a Black and Latino surgeon general. The purpose of the Surgeon General appointment is to serve as the Chief Medical Officer for both the Black and Latino church and the broader communities, supported by 37 major Protestant denominations. These individuals will address health priorities and strategies tailored to high-disease states within the community. Additionally, they will act as a spokesperson for the community, engaging with the White House, federal agencies, pharmaceutical companies, and Congress, to help shape fair and unbiased health policies for African-Americans.

Explaining Risks and Benefits to Encourage Clinical Trial Participation

Trust is missing in Black people and the healthcare industry. To build trust between researchers and study participants, transparency will be necessary. That is why trials are vetted for their potential risks and benefits before they become a part of the database. If information is not provided in a way that congregants can understand, they can not consent.

Who is the American Clinical Health Disparities Commission?

The American Clinical Health Disparities Commission (ACHDC), National Black Church Initiative (NBCI), and CME Outfitters (CMEO) today announced the launch of a partnership to address the dismally low recruitment, participation, and retention of African Americans in clinical trials.

Additionally, the partnership will aim to address health inequities and improve health literacy, messaging transcreation, and amplify the voice of the patient, particularly in marginalized and under-resourced communities.

ACHDC is a coalition created by African American and Latino clinicians and clergy to educate, generate interest, and improve clinical trial participation among NBCI constituents. NBCI is a coalition of 150,000 African American and Latino churches constituting 27.7 million members working to eradicate racial disparities in healthcare, technology, education, and housing for each of its members, congregants, churches, and the public.

CMEO is an award-winning accredited provider of continuing medical education with

Critical Data Collection

NBCI keeps an extensive database of clinical trials related to 11 chronic health conditions prevalent in the Black and Latino communities. Data collection is just as important as providing information on various conditions readily available for church members to explore their care options, and to discover best practices for treating their conditions, with social determinants of health taken into consideration. Through the databases and resources provided, vulnerable community members may find more straightforward access to care.

These seven approaches bolster the measures already taken by NBCI to ensure health equity. In 2017, the organization submitted a recommendation to the FDA for navigating the lack of participation in trials and at the height of COVID, distributed over 3.5 million first and second editions of Vaccnews to congregants.

While the NBCI has made great strides to help close the healthcare gap, their long term goal is to facilitate record participation in trials. Moving forward, that will take buy-in from the NIH, FDA, and pharmaceutical companies that recruit and carry out trials. Within the next five years, with the help of government and private entities, they hope to educate 150,000 to 300,000 people.

a substantial catalog of clinician and patient education focused on unconscious bias, health inequities, and diversity, equity, and inclusivity.



NBCI and the ACHDC Endorse National Academies Report on Improving Clinical Trials Representation

The National Black Church Initiative (NBCI), a coalition of 150,000 African African American churches and 27.7 million members, as well as the American Clinical Health Disparities Commission (ACHDC), endorse the National Academies Report on Improving Representation in Clinical Trials and Research and urge the FDA to use it as a blueprint.



Marcia McNutt, President of the National Academy of Sciences

In the report "Improving Representation in Clinical Trials and Research: Building Research Equity for Women and Underrepresented Groups" (2022), the National Academies recommends some easily understood and sensible ways to achieve diversity in clinical trials for women and African Americans. We need accountability built into any rules from the FDA.

The Rev. Anthony Evans, president of the National Black Church Initiative, says, "According to the Washington Post article titled, "Black Communities Endured a Wave of Excess Deaths in the Past 2 Decades", African Americans are dying at extraordinary rates, and we must find out the reasons WHY." Former President of the Florida Medical Association (FMA) and current Clinical Director, NBCI American Clinical Health Disparity Commission (ACHDC) Dr. Joseph Webster, MD, MBA, FACP states, "We need to find out whether or not new medicines work

More African Americans Need to Participate in Clinical Trials



by Dr. David Satcher, Physician, and Former United States Surgeon General

Every February our society measures its progress in the march toward equality as part of Black History Month. But seldom do we discuss inequality in health, an injustice that continues to plague African Americans.

A whole host of health disparities remains unaddressed, including Alzheimer's — a disease that African Americans are two to three times more likely to develop than non-Hispanic whites. This disparity is rooted as much in our cultural heritage as in our genes.

For years, studies have found that African Americans have a profound mistrust of doctors and scientists. on the physiologies of African Americans and Latinos. This is why we must increase our participation in Clinical Trials!"

The report states that both NBCI and ACHDC agree that the scientific necessity to improve research equity is urgent. The United States is becoming more diverse, with the 2020 U.S. Census finding that the number of people who identify as White has decreased for the first time since the U.S. Census started being taken in 1790. Deep health disparities are persistent, pervasive, and costly despite greater diversity.



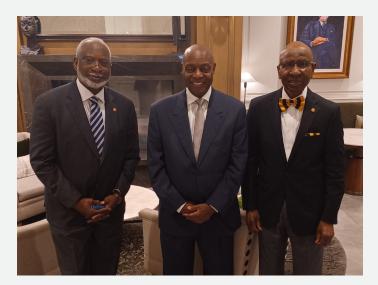
Without major advancements in the inclusion of underrepresented and excluded populations in health research, meaningful reductions in inequalities in chronic diseases such as diabetes, cancer, and Alzheimer's remain unlikely. Purposeful and deliberate change is needed. As the United States becomes more diverse every day, failing to reach these growing communities will only prove more costly over time.

Consequently, we participate in clinical trials at far lower rates than other ethnic groups, which helps to perpetuate the sort of disparities seen with diseases such as Alzheimer's. This fear of clinical trials dates to a dark chapter in our shared history: the Tuskegee syphilis experiments.

The Tuskegee study was an infamous clinical experiment in which researchers and the U.S. Public Health Service led African American men with syphilis to believe that they were receiving free medical care while, unbeknown to them, they were being left untreated so scientists could study the effects of prolonged syphilis.

After the Associated Press exposed the truth, sparking a public outcry, the U.S. government ended the study in 1972, 40 years after it began. The 1974 National Research Act set new guidelines for the use of humans in clinical studies. In 1997, the Clintonadministration worked with higher education institutions to usher in new training requirements and ethical standards for physicians, researchers and

medical students as part of an official apology President Bill Clinton issued on behalf of the nation to the victims of the experiments. While these standards go a long way toward helping to prevent future such experiments, much damage was already done among African Americans.



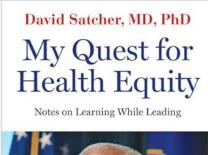
More than 40 years later, memories of the Tuskegee study have not faded, nor should they. But we should not allow the horrors of that study to loom over us to our detriment, and increasing African American enrollment in clinical trials is critical. We can start by better equipping physicians with easy-to-access information about the location and requirements of clinical trials so doctors may more easily refer their qualified patients. Without higher levels of participation among African Americans, we will never unlock the root causes of the disparate impact of a disease such as Alzheimer's.

Every day that African Americans continue to live in fear of such trials is another day that we fall further behind in the fight against Alzheimer's and other diseases.

Alzheimer's has major health implications for African Americans but also has a huge impact on families' financial stability. In 2012, African Americans accounted for one-third of the cost of care — around \$71.6 billion — for Alzheimer's, despite accounting for less than 14 percent of the population, researchers at John Hopkins University found in 2013. While Medicare and Medicaid bear most of the costs of medical bills associated with Alzheimer's care, African Americans paid more than \$3.45 billion out of pocket on care in 2012. Then there is the high toll of informal care, which is about 61 percent of the cost of Alzheimer's for African Americans. Sadly, this type of care can have even deeper economic repercussions as more and more African Americans drop out of the workforce or delay college to care for their loved ones.

Alzheimer's cases in the United States are projected to triple from 5.2 million to nearly 14 million by 2050.

In other words, these problems are going to get worse before they get better. Researchers believe it is possible to stop Alzheimer's with investments in research equal to the size and scope of the disease. But funding can go only so far without a corresponding increase in patients willing to participate in innovative clinical trials. As one of the groups that has the most to gain from Alzheimer's clinical trials, African Americans should lead by example. In doing so, we just might gain meaningful insight into the causes of the disparate impact of Alzheimer's and help speed our pace to a cure.





We might also finally escape the shadow cast by Tuskegee that has helped to perpetuate a form of inequality in health care, something Martin Luther King Jr. called the worst of all types of inequalities. That would be a fitting way to honor those who went looking for care only to find injustice.

This article first appeared in the Washington Post Opinion section Feb 21, 2014

MSM Researcher's Global Team Wins \$25 Million Cancer Grand Challenges Award



Focusing on cancer inequities, Team SAMBAI, led by Dr. Melissa Davis, is the only winning team in the U.S. led by an African American woman.

Morehouse School of Medicine (MSM) today announced Team SAMBAI, a global team led by Melissa B. Davis, PhD, director of the MSM Institute of Translational Genomic Medicine, has been awarded a \$25 million grant funded by Cancer Research UK and the National Cancer Institute, through Cancer Grand Challenges, to address cancer disparities in populations of African ancestry, becoming the first Cancer Grand Challenge awardee to focus on cancer inequities.

Called Team SAMBAI (Societal, Ancestry, Molecular and Biological Analyses of Inequalities), Dr. Davis is leading an interdisciplinary research group from the United States, Ghana, South Africa, and the United Kingdom. The award not only marks the first one to focus on health disparities and to be led by an African American woman, but it is also the first one awarded to a researcher at a Historically Black Medical School and is the first one given to a host institution in MSM's home state of Georgia.

"We are so incredibly proud of Dr. Davis' leadership in directing the effort to create a truly historic and precedent setting winning proposal to Cancer Grand Challenges that holds the potential to have a tremendous impact on how we treat cancer for people with African ancestry," said MSM President and CEO Dr. Valerie Montgomery Rice. "For nearly 50 years, the driving mission of Morehouse School of Medicine has been to address health inequities for communities of color, and we are honored to have the unique opportunity to carry that mission forward in partnership with Cancer Grand Challenges."

"I want to extend my appreciation to Cancer Research UK, the National Cancer Institute, Cancer Grand Challenges, my Team SAMBAI colleagues around the world, and my Morehouse School of

SALEM MISSIONARY BAPTIST CHURCH Sharing the Gospel from Generation to Generation STEWART SCHOOL BOOM SUNDAY SCHOOL BOOM DIN PERSON SERVICE SUNDAY 10:45 AM DR. JAMES A. THORNTON Pastor

Medicine family on being selected one of five world-class global research teams to win this award," said Dr. Davis.

"We are looking forward to engaging into what we hope will be groundbreaking research that will shift the paradigm for cancer inequity amongst people of African descent and hopefully help to save lives in the future."

NBCI Salutes Dr. Richard Allen Williams



Richard Allen Williams is an American physician who founded the Association of Black Cardiologists. He previously served as the President of the National Medical Association.

Dr. Richard Allen Williams was born and raised in Wilmington, Delaware, the youngest of eight children. Upon graduating from Howard High School at the top of his class with a 4.0 grade-point average, he was awarded a full scholarship to Harvard University from which he graduated with honors as the first African American student at Harvard from Delaware.

He received the M.D. degree from the State University of New York Downstate Medical Center, performed his internship at the University of California San Francisco Medical Center, Internal Medicine residency at the Los Angeles County-USC Medical Center, and Cardiology fellowship at Harvard Medical School and Brigham and Women's Hospital in Boston.

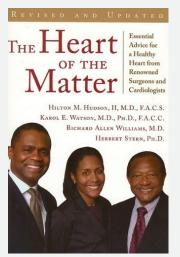
He was an instructor in Cardiology at Harvard Medical School, and while in this position, he founded and directed the Central Recruitment Council of Boston Hospitals, which recruited significant numbers of Black medical trainees to Boston hospitals for the first time in their history.

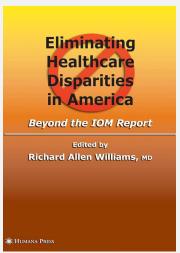
He then served for three years as the inaugural Assistant Medical Director at the Dr. Martin Luther King, Jr. Hospital in Watts, California, and was charged with the responsibility of opening the hospital. During this time, he and Dr. David Satcher collaborated on writing the grant proposal, which was awarded \$2.5 million by the National Heart, Lung and Blood Institute of the National Institutes of Health to

establish the King-Drew Sickle Cell Center, of which he became the Director. Following this appointment, he took a position as Chief of the Heart Station and Coronary Care Unit at the West Los Angeles VA Hospital, eventually becoming head of Cardiology at that institution as well as the first Black full Professor in the history of the Department of Medicine at the UCLA School of Medicine.

Dr. Williams has numerous publications and awards and is the author of The Textbook of Black-related Diseases, published by McGraw-Hill in 1975. This is a 900-page book that detailed medical conditions peculiar to African Americans; no other book of its kind has been written before or since, and it is widely considered the classic seminal work on the medical status of Blacks. It is on the shelves of libraries and medical schools worldwide, including the Library of Congress. Other recent books are The Athlete and Heart Disease: Diagnosis, Evaluation and Management and Humane Medicine: A New Para-

digm in Medical Education and Health Care Delivery. Both of these books were published in 1999 by Lippincott Williams & Wilkins. Two other books by Dr. Williams are in preparation: The Textbook of Ethnic Medicine, and The History of Blacks in Medicine. In 2000, he also published volume II of Humane Medicine.





THE NATIONAL BLACK CHURCH INITIATIVE (NBCI) CLINICAL LECTURE TOUR



A Historic Analysis of Medical Abuses and Promises of the Future Benjeil Z Edghill, MD, Chair of the Ophthalmology Section of the National Medical Association has practiced in Staten Island the past 15 years as the only glaucoma fellowship trained ophthalmologist on the island. Dr. Edghill has taken care of thousands of patients and is an expert in the latest medical, laser, and surgical treatments of glaucoma and cataracts. - tinyurl.com/bdfjj9su



The Role of African American Physicians to Enroll African Americans in Clinical Trials Dr. Patricia Whitley-Williams M.D., FAAP, Professor of Pediatrics at Rutgers Univ. discusses the role African American physicians can take to enroll African Americans in clinical trials. She is a member of the Advisory Committee on Immunization Practices at the CDC and the National Network for Immunization Information of the Infectious Diseases Society of America. - tinyurl.com/yv4mdc5r



Rev. Anthony Evans Co-Hosts Lecture: 'Why Health Disparities Are Everyone's Problem' Rev. Anthony Evans and host Kelly Wright of "The Kelly Wright Show" on Black News Channel (BNC) speak with Dr. Lisa A. Cooper, MD, MPH, FACP. She is Director of the Johns Hopkins Center for Health Equity and author of the book, "Why Are Health Disparities Everyone's Problem?" - tinyurl.com/4bumkmmn



Rev Anthony Evans Discusses the Need for Black Co-Investigators in Clinical Trials The NBCI Clinical Trials Lecture Tour present Dr. Joseph L. Webster, Sr., MD, MBA, FACP and Dr. James McCoy, MD, who answered questions concerning clinical trials. Dr. Joseph Webster, MD is a Gastroenterology Specialist in Tallahassee, FL, Dr. James McCoy, MD is a general surgery specialist in Atlanta, GA. - tinyurl.com/52jnkktp



Rev. Evans Discusses Issues in Recruitment for Clinical Trials w/Dr. Fabian Sandoval Dr. Fabian Sandoval, CEO & Research Director, has over 25 years of bench to bedside research experience. His diversified research career has been in academia, healthcare systems and the public sector. He is also the host of the Emmy award winning Telemundo program "Tu Salud, Tu Familia" (Your Health Your Family). - tinyurl.com/ytrsyrt3



The State of African Americans and COVID-19: Where Do We Go From Here? The National Black Church Initiative is proud to present Dr. Macaya Douoguih, MD, MPH, Head, Janssen Clinical Development and Medical Affairs, Vaccines, who will give the inaugural lecture of its National Clinical Lecture Tour. We also welcome BIO and Janssen Pharmaceutical as our partners. - tinyurl.com/bdhr77sy

WHY ARE SO MANY BLACK PATIENTS DYING FROM HEART FAILURE?

We have to create a more robust pipeline of Black medical and research talent, which can overcome a historical mistrust of the medical community stemming from past abuses.

Dr. Alanna Morris and Robert Blum



Dr. Alanna Morris is an associate professor of Medicine at Emory University



Robert Blum is the Henry Crown Fellow at the Aspen Institute and CEO of Cytokinetics.

Heart failure stubbornly remains a leading cause of death in this country. Moreover, our own failures to do something about it are disproportionately impacting the Black community. In fact, ZIP code matters substantially more than genetic code in determining health outcomes. Black patients are dying from heart failure at considerably higher rates than white patients.

This should set off alarm bells, but sadly that has not been the case. We need to deploy available resources, public and private, to address not just the heart failure epidemic gripping our nation, but also the unparalleled and unjustifiable health inequities for our most vulnerable.

The problem unsurprisingly stems from a long history of systematic racism and the poverty it has caused. Accessing quality medical care is much harder for many Black patients. Clinics are too frequently located far from their homes and taking off time from work, finding child care and arranging transportation all contribute to the many challenges Black patients face before they even arrive at a point of care.

Barriers to care for Black patients

Once there, Black patients are <u>less likely</u> to be treated by a cardiologist, which can result in cases going undetected and poorer outcomes for patients. Health care costs are at the center of why many Black patients do not pursue medical care. A large number may be

without insurance or lack sufficient coverage to pay for hospitalization.

Medicines remain expensive, and there are too few resources available to support those unable to afford proper treatment. In cases where financial assistance does exist, patients and doctors might be unaware of the options or find themselves mired in daunting application processes.

Perhaps even more shocking are the lives lost due to insufficient knowledge. We see that a lack of access to adequate, authoritative medical experts and information about heart failure remains a major contributor to the very high prevalence of heart disease in the Black community.

There are quite simply not enough resources and experts able to connect to those at highest risk. It has also led to lower levels of participation in clinical trials for potential new treatments and fewer <u>Black heart failure</u> specialists, community cardiologists and medical science researchers.

We are awakening to a new dawn however, one on which industry must now join forces with health care providers to elaborate on patient engagement.

There is a desperate need for new public awareness initiatives about the disease that are created by and focused on the Black community. We have to create a more robust pipeline of Black medical and research talent, which can overcome a historical mistrust of the medical community stemming from past abuses, as well as more diversity in clinical trial enrollment.

However, enhanced education and awareness are insufficient if not also coupled with greater access as measured in reach, frequency, affordability and equitable treatments.

Health care's 'valley of death'

Pharmaceutical companies can help by providing financial bridges for uninsured and underinsured patients, and help cover the cost of medicines during the often lengthy gap between a drug's Food and Drug Administration approval and Medicare coverage – a span the Centers of Medicare and Medicaid Services describes as "the valley of death."

No one should die because of bureaucratic delays, nor should intermediates like pharmacy benefit managers remain cloaked behind transparencies and their role in excessive drug costs.

The bottom line in heart failure is both measured in dollars and deaths. Racial inequality of this magnitude demands a large-scale government response. The heart failure epidemic in America needs to be declared a national public health emergency.

The absence of heart failure – and even more glaring, heart disease, as the No. 1 cause of death in this country – from President Joe Biden's "moonshot" initiative – which includes cancer, diabetes and Alzheimer's – is inexplicable given the toll heart failure is having on American families across the board and in particular the Black community.

We need to dedicate more federal research funding to developing new treatments for this massive burden on our nation's health care system.

Developing and delivering new medicines that improve patient outcomes is essential but takes time. However, we can no longer be patient in addressing long standing racial inequities facing patients who are Black men and women struggling with heart failure.

We must also be triaging and treating the underlying afflictions to our health care systems with sufficient speed and scale to ensure all patients receive the treatments they deserve.

We need a national call to action initiative to identify care service programs that incentivize providers to expand into these areas, as well as initiatives to overcome social determinants to health care. Our Department of Health and Human Services must explore public education campaigns on heart failure reaching and resonating with the Black community, similar to those used effectively during the COVID-19 pandemic.

Heart failure is itself an epidemic, and the fact that it so disproportionately impacts Black patients is a national tragedy. We must see rapid, robust public and private efforts invested in saving these lives.

The credibility, efficacy and equality of our health system depends on what we do at this moment.

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