

CLINICAL TRIALS EDUCATION AWARENESS AND PARTICIPATION PROGRAM (CTEAPP)

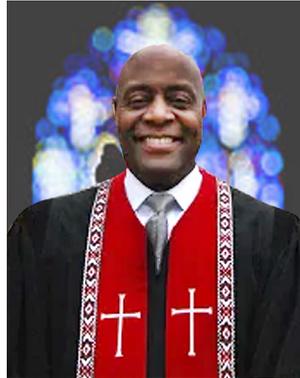


The National Black Church Initiative

The National Black Church Initiative (NBCI) is a coalition of 34,000 African American and Latino churches working to eradicate racial disparities in healthcare, technology, education, housing, and the environment. NBCI's mission is to provide critical wellness information to all of its members, congregants, churches and the public. The National Black Church Initiative's methodology is utilizing faith and sound health science.

The National Black Church Initiative's purpose is to partner with major organizations and officials whose main mission is to reduce racial disparities in the variety of areas cited above. NBCI offers faith-based, out-of-the-box and cutting edge solutions to stubborn economic and social issues. NBCI's programs are governed by credible statistical analysis, science based strategies and techniques, and methods that work. Visit our website at [*www.naltblackchurch.com*](http://www.naltblackchurch.com).

Letter from Rev. Anthony Evans



Dear Colleagues,

We wanted to let you know about this exciting effort by 34,000 African American churches comprising of 15 denominations and 15.7 million African Americans to increase the participation of African Americans in clinical trials.

The National Black Church Initiative has developed a proven method to motivate, educate, persuade and encourage its membership. NBCI possesses all of the major target populations in literally every disease state within its congregational network. With your help we can harness this partnership and this valuable resource to move our country further in the area research and answering the question of how and why?

The National Black Church Initiative intends to provide the necessary leadership with this initiative – The National Black Church Initiative Clinical Trial Education Awareness and Participation Program.

This booklet illuminates our health model (HED), our strategy and our program of achieving that goal. This is an exciting but unusual initiative by the faith community. This new method of combining scientific strategies in a faith-based environment to produce a more educated and robust congregant who will understand and grow to cherish the value of participating in clinical trials.

The mistrust of government and pharmaceutical industry must finally be transformed into a relationship of trust; informed consent and the black community must finally begin to reap the benefits of clinical trials.

This booklet will help any university, pharmaceutical or private research organization understand the dynamics of attracting African Americans towards clinical trials with the assistance of the National Black Church Initiative.

Sincerely,

Rev. Anthony Evans
President



TABLE OF CONTENT

The National Black Church Initiative (NBCI) Mission Statement

Letter from Rev. Anthony Evans	i
Dr. Owen Garrick, MD, MBA	ii
Dr. Doris Browne, MD MPH	iv-v
NBCI Clinical Trials Education Awareness and Participation Program (CTEAPP)	1
Health Emergency Declaration (HED)	6-7
NBCI Clinical Trial Activities since 2009 to Present	8
• NBCI Behavioral Team	8
• Project I.M.P.A.C.T. Increase Minority Participation and Awareness of Clinical Trials ...	9
NBCI Program Experience in Clinical Trials and Supporting Materials	10-11
• Multiple Myeloma (Novartis)	12-14
• COPD (Boehringer Ingelheim)	15
• Autism	16

Appendices

How NBCI is Organized	16
NBCI Faith Communities by Location Gender and Race	17-19
NBCI Health-At-A-Glance	20
NBCI Corporate Capability	22

Owen Garrick, MD, MBA



Dr. Owen Garrick is President & Chief Operating Officer of Bridge Clinical Research. Bridge Clinical is the leading organization focused on increasing the diversity of clinical trials for both patients and investigators. BCR is active in therapeutic areas where Blacks have a high burden of disease such as Oncology, Endocrinology, Immunoscience, Anti-Infectives (HIV, HCV) and cardiovascular disease.

While at Bridge Clinical, Dr. Garrick has lead the design of patient recruitment campaigns, helped sponsors develop protocols that take into account minority health and developed minority investigator networks for studies. Prior to Bridge Clinical Research, Inc., Dr. Garrick was the Director of Corporate Strategy and Business Development at McKesson Corporation. He pursued vertical integration opportunities with generic drug manufacturers and upstream product development. He also developed and launched the company's Drug Adherence Business focused on pharmaceutical and biotechnology manufacturers.

He also served as Executive Director and Co-Head of Mergers & Acquisitions at Novartis Pharmaceuticals. In this position, he led all global M&A activity up to \$5 billion. He specifically oversaw small and medium size company acquisitions, hybrid equity/license right deals, mature product divestments, and venture investments in biotechnology companies.

Previously he spent four years at Goldman Sachs in New York, functioning as an investment advisor working with private healthcare companies as they sought to grow, raise capital, and perform initial public offerings. Dr. Garrick earned his MD from the Yale School of Medicine and his MBA from the Wharton School of Business. He holds an AB in Psychology from Princeton University and continues to be an active alumnus, serving on the Alumni Council Executive Committee. He also serves on other boards and professional committees, including the HHS Secretary's Advisory Committee for Human Research Protections and Quorum Review IRB.

Doris Browne, MD MPH

Newly elected President of the National Medical Association



Dr. Browne is the newly elected President of the National Medical Association and President & CEO of Browne and Associates, Inc. (BAI) which is dedicated to providing health information and education services. Dr. Browne is the former Program Director in the Division of Cancer Prevention at the National Cancer Institute (NCI) where she managed the breast cancer chemoprevention portfolio. Dr. Browne is National Black Church Initiative Medical Director.

Dr. Doris Browne, MD, MPH President & CEO has more than 30 years of experience in executive medical management and leadership at the national and international levels. She is well published including textbooks, book chapters, and articles. Throughout her career, she has been dedicated to eliminating health disparities focusing on prevention, health education, and wellness programs. She has served as Principal Investigator, Program Manager and a consultant for Medical Care Development International; Systems Assessment Research Corporation; and Synergy Enterprise Incorporate. She is a retired Colonel of the US Army Medical Corps.

Her background includes clinical care, research, public policy initiatives, pharmaceutical studies, clinical trials, disease prevention and a wide range of health care delivery issues. She served as Chairperson, Breast Cancer Education and Prevention Initiatives, planned and implemented conferences and workshops. She was a Woodrow Wilson Public Policy Scholar (2007) at the Woodrow Wilson International Center for Scholars where her research focused on estrogen receptor negative breast cancer health disparities. Colonel Browne's military experience includes responsibility for the biomedical research programs for the Army and the Department of Defense (DoD); Health Affairs' prevention and standards for analysis, review, and formulation of policies, guidelines and programs on women's health issues, oversight for health promotion and disease prevention, and TRICARE preventive benefits; planning the disaster medical management support for radiation accidents/incidents including management of radiation casualties, training and technical assistance in HIV/AIDS, clinical trials, and chronic disease management.

Dr. Browne serves on numerous Boards and committees. In her early career she developed an education manual on sickle cell anemia for the former Department of Health, Education and Welfare (now DHHS). Dr. Browne graduated from Tugaloo College (BS), University of California at Los Angeles (MPH), and Georgetown University (M.D.) and completed an internship, residency, and fellowship at Walter Reed Army Medical Center. She achieved national and international recognition as an expert in the medical management of radiation casualties, women's health, breast cancer, and HIV/AIDs. She was the DoD representative to the National Action Plan on Breast Cancer. She is a former Chair of the Cancer Research Committee of the National Medical Association (NMA) and is its representative to the National Breast Cancer Awareness Month (NBCAM) Board of Sponsors. Dr. Browne served as Chair of the Government Liaison Committee for the American Medical Women's Association and is a member of the Governing Board of the Intercultural Cancer Council and Medical Care Development. She has served as a reviewer for both public and private grant applications.

She is Secretary of the Board of Trustees of Tugaloo College, member of numerous professional societies and organizations including the National Medical Association, American Society of Clinical Oncology (ASCO), African Organization for Research and Training in Cancer (AORTIC), American College of Physician (ACP), American College of Physician Executive (ACPE), Leadership Washington, Trinity Episcopal Church, and others. She is the 2007 recipient of the Minorities in Research Sciences' award for Professional Achievement and the 2010 recipient of an NIH Merit Award.



NATIONAL BLACK CHURCH INITIATIVE

CLINICAL TRIALS EDUCATION AWARENESS AND PARTICIPATION PROGRAM (CTEAPP)

The National Black Church Initiative (NBCI) is a faith-based coalition of 34,000 churches comprised of 15 denominations and 15.7 million African Americans working to eradicate racial disparities in healthcare, technology, education, housing, and the environment.

NBCI's mission is to provide critical wellness information to all of its members, congregants, churches and the public. NBCI's methodology utilizes faith and sound health science.

The NBCI Clinical Trials Education Awareness Participation Program (CTEAPP) is another groundbreaking initiative, housed under NBCI's Health Emergency Declaration (HED) NBCI has always and will continue to hold itself to the highest ethical standards while advocating clinical trials participation in our faith-based communities. The mission of the NBCI clinical trials program is to increase the representation of African Americans in clinical trials. It is imperative that African Americans participate in clinical trials to assure that our population receives the benefits of cutting edge drug therapies and modern medicine.

CTEAPP is a critical component of our work in eliminating health disparities. NBCI seeks to educate our member churches and their congregants of the value, benefits, protections, and promise clinical trials can offer for participants. In doing so, NBCI itself must be assured of the protections and the appropriateness of clinical trial protocols. Therefore, we have adopted a set of core principles that will govern our decisions regarding involvement in clinical trials:

Principle 1

Education and awareness are key in getting Blacks to participate in clinical trials. The published literature is replete with studies that show the Black patients have a similar to higher willingness to participate in clinical trials. As such, NBCI believes that there must be thorough education covering the potential risks and the benefits to patients in any clinical trial. We have found that an educational program that highlights the following can be done cost effectively and within the confines of a study's recruitment period:

- An overview of the disease in question and why it matters to Black people
- Previous participation rates of Blacks in prior studies within the therapeutic area, the class of drug or the specific program within the sponsor
- Why Blacks should participate in clinical trials, generally
- Why Blacks should participate in clinical trials within this class (either generically or for a specific study)

- How patients are safeguarded
- Ongoing informed consent process
- Proper review and approval by a duly constituted and certified Institutional Review Board;
- Resource accessibility for answering all participants' questions in a culturally and linguistically appropriate manner.

Principal 2

Culturally and linguistically appropriate literature, video, and web based education modules are critical to reach Black audiences concerning the trial. NBCI has regular success with the following approaches:

- Health Note
- Health Sermon
- Health-At-A-Glance

Principle 3

NBCI will advocate for patient participation in clinical trials with investigators who have been trained in Good Clinical Practice regulations, ethics, and cultural competence.

Principle 4

NBCI requires that there be adequate resources to launch and sustain a church/community based awareness program regarding all aspects of the trial.

Principle 5

NBCI must be adequate resources for the completion of the clinical trial and for reporting the knowledge of benefits and risks for diverse populations participating in the trial.

NBCI/CTEAPP Partnership with Bridge Clinical Research

Bridge Clinical Research (BCR) provides recruitment strategies and solutions to address the unique challenges surrounding minority participation in clinical trials. BCR works directly with major pharmaceutical and biotech companies to provide a technology, service, and support solutions aimed at reducing clinical development timeframes and enhancing minority patient recruitment efforts. BCR provides the necessary training and certification to medical practitioners interested in participating in clinical trial research, and assists clinical research investigators and urban hospital and clinic systems with minority patient recruitment efforts. As part of our services, BCR communicates with investigators, sponsors, and clinical research personnel, resolves medical issues, provides medical input for regulatory documents, supports business development activities, and provides Serious Adverse Event (SAE) consultation.

BCR clinical trials personnel maintain professional knowledge and skills, particularly in the areas of FDA/ICH guidelines and regulations. BCR also has core strengths in clinical operations, creative, marketing, messaging, and minority health to provide an end-to-end solution for recruitment of minority subjects into clinical trials.



NBCI/CTEAPP Lecture Series

The National Black Church Initiative is initiating a ten-part nationwide lecture series that will highlight noted African American clinicians and to further NBCI Clinical Trials Education Awareness and Participation Program (CTEAPP). The lecture series is another important building block of creating an expansive clinical trials initiative to increase minority participation. The goal of NBCI/ CTEAPP is to assure 15 percent or more black participation in clinical trials.

There are three goals of the lecture series

1. Highlight the extraordinary partnership forged between Bridge Clinical and the National Black Church Initiative --- combining science and faith.
2. Identify expert African American Clinicians who can serve as primary investigators in major clinical trial programs.
3. Build a list of 100,000 key African American stakeholders who are supportive of African American participation in clinical trials along with NBCI/HED Volunteer Health Corp.

We hope to galvanize and identify 2,500 key community stakeholders in each city of NBCI Churches who are in the health space and understand the historic importance of this movement by NBCI Clinical Trials Education Awareness Participation Program. We plan to turn these individuals into clinical trial advocates. We will provide them with the training, education, and information they need. They will our frontline advocates when we need to identify potential participants in a particular clinical trial. We plan to provide online training through a new website called [www.blackchurchand clinicaltrials.com](http://www.blackchurchandclinicaltrials.com). This online educational portal for African American church members and their families will allow them to search for clinical trials of their choosing.

The website will also serve the following functions:

1. Serve as a clearinghouse of information concerning the value of clinical trials and how to prepare oneself to participate in a clinical trial.
2. Underscore the importance of informed consent. It will provide information for our members on what questions to ask and what investigator questions may be unethical.
3. Keep a historic database on clinical trials that are considered unethical and underscore the reasons why the black church is trying to repair and clear up the past and set a brighter future around clinical trials and African Americans.
4. Train, equip, and empower key African American stakeholders to help NBCI reach its goal of encouraging African Americans to participate in clinical trials at a rate of 40 percent.
5. Highlight population health concerns and underscore clinical trials' impact on individual health through what is learned in the study.

The lecture series will cover a variety of diseases that currently have a major impact on African American mortality rates. It also will deal with whose disease states that affect quality of life, covering all genders and ages. We are focused on bringing together experts who will provide critical information that will dramatically affect both health disparities and clinical trial participation. With NBCI's 34,000 member churches, and with the balance of 150,000 African American churches in the country, it should have a significant and sustaining impact.

The disease states we plan to cover are:

1. Lupus/Black Women's Health
2. Rare Diseases/Infectious Diseases (HIV)
3. Diabetes
4. Eye Care and Blindness
5. Cancer
6. Heart Disease
7. Hypertension
8. Multiple Myeloma/Blood Diseases
9. Nutrition and Obesity
10. Autism

NBCI understands the importance of clinical trials for African-Americans. It is important that African-Americans are proportionately represented in clinical trials for common diseases such as Diabetes, AIDS, cancer and heart disease that affect African Americans disproportionately. For the past four years NBCI has conducted seminars in its faith communities to encourage more African Americans to participate in clinical trials. NBCI believes it has finally reached a point where it can begin to encourage African Americans to participate in clinical trials in larger numbers. NBCI feels that all clinical trials should be conducted with the highest of ethical standards and adhere to current federal laws, rules, and regulations that govern these trials. It is critical that these protocols are in place before NBCI or NBCI member congregates endorse or participate in any clinical trial regimen.

Our objective is to avoid the ghost of Tuskegee.

The following issues should be settled before any participation occurs:

- There must be a signed consent form.
- There must be an education session explaining the purpose and value of the clinical trial, and its possible outcomes in terms of data and the management of a particular disease.
- There must be education on the effects of drug therapy or therapy in general.
- There must be adequate coverage for all unforeseen possibilities.
- All government protocol in reference to safeguards must be adhered to.
- The individuals who agree to participate should follow the clinical trial's instructions in order to achieve the best results.

- All possible side effects of the clinical trial must be explained fully and in writing.
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 - All government protocol in reference to safeguards must be adhered to.
 - The individuals who agree to participate should follow the clinical trial's instructions in order to achieve the best results.
 - All possible side effects of the clinical trial must be explained fully and in writing.
 - All clinical trials must be reviewed by NBCI's medical consultant.

There are three critical reasons why NBCI is supportive of clinical trials. The first is that they are a way in which people can receive cutting-edge drug therapy and medical coverage when the individual does not have health insurance, or has a limited form of health insurance.

Secondly, it is critical for African Americans to be represented in these trials so that researchers can understand the differences in physiological effects of drugs concerning the racial minority as opposed to the majority. The third is that these trials may help society create a cure or an effective drug management technique that will reduce the suffering and mortality of those groups of people who suffer from a chronic or fatal disease.



HEALTH EMERGENCY DECLARATION (HED) EXECUTIVE SUMMARY

The National Black Church Initiative's Health Emergency Declaration (HED) is a landmark program initiated by NBCI leadership, making strides to help bring about positive change in the physical health of the African American community. HED aims to institute throughout its 34,000 member churches proven health prevention strategies and models that will begin to alter, transform and eliminate the negative health disparities between African Americans and the majority population of the United States. Launched March 2010 in Baltimore, Maryland, this seven-year commitment pledges to help bring about healthier lifestyles in African Americans through education, promotion of preventative care, improved diet, physical exercise, and clinical trials.

HED is designed as an innovative health prevention strategy that has the capacity to accommodate and provide integrative support of existing program systems. It is not designed as a stand-alone system, but will realize the full strength of its unique structure when fully or partially integrated into existing health systems that have proved to be effective in dealing with health disparities. The program's structure is designed with flexibility in order to accommodate forthcoming health reform models. The elasticity of HED will lie in the hands of the 35 Health Panels that will be able to amend their strategic plans and structure to accommodate any significant healthcare system change without compromising on the original intents of HED.

Health disparities between minority populations and mainstream America are a critical problem in our country. African Americans disproportionately suffer from more chronic diseases, suffer from more malnutrition, and lack the resources needed to be properly educated about a healthy lifestyle due to societal structures outside their control. The most compelling reason that catalyzed HED's creation stemmed from the unfortunate circumstance that every major effort by all levels of government, health foundations, and private health organizations has had little to no impact in sustaining good health practices in the black community. Past efforts by these institutions have been half-baked, strategically flawed, and vastly underfunded. This means that having a sustaining impact on the incidence of chronic diseases is nearly impossible and the amount of change in behavior of the individuals that the programs are targeted for is nil. NBCI's HED initiative seeks to help remedy these problems at a pace that is just, fair, and desperately needed in the African American community.

Rev. Anthony Evans, President of NBCI, piloted HED as a health model for the black church. The program is a comprehensive seven-year plan aimed at tackling the tragic state of health in the black community. Through the establishment of 35 Health Prevention Communities, HED plans to educate communities across the country and promote preventive healthcare. Because of the church's leading role in the black community, HED will have a greater and lasting impact on the African American community and seriously help to decrease the health disparities that plague it.

HED is a science-based health model that works within the traditional function of the black church. It promotes education, screening, data collection, clinical trials, and conducts health surveys throughout its 35 health prevention communities. It is grounded in seven Core Values, thoughtfully considered at the program's inception as the primary means to affect the change needed in the African American community.

Those Core Values are: Knowing Your Body; Visiting the Doctor; Increasing Fruit and Vegetable Intake; Increasing Physical Activity; Getting Enough Sleep; Reducing Stress by Taking Mental Breaks; and Quitting or Not Starting Smoking. 3

To accomplish its HED goals, NBCI will strategically redefine its relationship with every segment of the healthcare industry, including government. It will also engage up to 75 percent of African American congregations, touching some 15.7 million individuals and galvanizing more than 75,000 volunteers. A health economist is still evaluating the cost savings of this initiative over the next seven years. The guiding principle for HED is that our program will not participate in any program that does not seek as its primary goal to eliminate the health issues in the Black community, does not try to reduce the number of chronic disease cases in the Black community, or does not attempt to strengthen the existing health models in the U.S.

Due in large part to NBCI's unique and strong ties with the Black Church, HED has experienced measured success in its first several years. Beginning with its launch in Baltimore, HED has implemented a range of advocacy initiatives in over 30 communities across the country. Partnering with such notable firms as Novartis, HED has successfully worked to better African American health around the issues of HIV/AIDS, multiple myeloma, and COPD. With its momentum still in high gear, NBCI leadership looks forward to continuing its HED programming around other critical health issues facing the African American community. NBCI is constantly on the lookout for any health entity or advocacy organization that is an innovator in the field, with the ideas and the passion to help eradicate some of the chronic disease states that are plaguing the Black America today.

The African American community in the United States can ill afford to wait for health reform undertaken by the government, whose effects may not truly take hold for another decade. For detailed information about NBCI's Health Emergency Declaration and its work to close health disparity gaps impacting African Americans across the United States, visit our website at <http://www.naltblackchurch.com/health/> to read the entire plan.

NBCI Clinical Trial Activities Since 2009 to Present



NBCI Behavioral Team

Last November, 2014 we brought together 3 African-American social psychologists to create NBCI/HED Behavioral Team. The focus of these 3 psychologists was to survey the literature, find out what is available concerning African-American health behavior and lifestyle. We wanted to ask the question, “What are some of the behavioral traits that lead to bad health choices given the extraordinary negative health statistical outcomes?”

There are four things we hope to glean from this investigation;

1. An exhaustive review of the literature concerning African-American’s behavior and lifestyle choices.
2. Based upon the literature and other scholarly documents, is there a research gap in this area of African-American behavioral traits and is has there been any comprehensive study on health behaviors among African-Americans by African-American higher educational institutes or other research consortiums?
3. What is the economic cost of conducting a comprehensive behavior survey to help close the research gap in this area if one exists?
4. Can we glean from the present literature any well-known negative health traits that must be addressed?



Project I.M.P.A.C.T. Increase Minority Participation and Awareness of Clinical Trials (National Medical Association)

The National Black Church Initiative was asked to work with Dr. James Powell of Project Impact to help increase the number of African-Americans participating in clinical trials. We have participated in 13 separate clinical trials conferences that have been held in our churches around the country. These conferences featured National Medical Association doctors who discussed the values of clinical trials and why members of the faith community should not be afraid to participate. They were extremely successful. The 13 conferences reached 92,000 of our members with clinical trials education and literature.

Some of the cities were St. Louis, MO, Los Angeles, CA, Dallas, TX, Richmond, VA, New York, NY, Columbus, SC, Savannah, GA and others.

4. We will administer a 5 question survey to 35,000 parishioners throughout the country concerning the views on clinical trials.
5. We will produce a YouTube video concerning clinical trials and blast it to our membership 10 times over the next three months.

Results

We have informed each of our faith command leaders of the forthcoming clinical trials training portal and educational session.



NBCI Program Experience in Clinical Trials and Supporting Materials

Johns Hopkins

Brief description of project (health issue, objectives of program, etc.)

NBCI was recruited by a clinical trials provider to work as a third party agent for a Johns Hopkins study on hypertension in African-Americans.

Number of people who participated in the educational series or received literature

There were five educational sessions over a four month period, 962 people participated in the sessions.

6554 people received literature concerning the clinical trials.

Number of people who screened for the research study

We are unaware. We were not included or informed of the results of the screenings.

Number of people who enrolled in the research study

452 was the number we were given of people participating in the study.

COPD (Johns Hopkins study)

Brief description of project (health issue, objectives of program, etc.)

As determined by the NBCI HED Health Committee, the twelve-week demonstration project was applied to 52 additional African-American churches instead of the original 12 to create a substantial sampling that would illustrate the need in the African-American community for COPD education.

Number of people who participated in the educational series

We confidently approximate that over 100,000 NBCI members were impacted.

Number of people who screened for the research study

Health screenings were conducted at over 50 churches, impacting over 30,000 congregants.

Number of people who enrolled in the research study

We gave Johns Hopkins permission to utilize our statistical data on their research study. We were paid for this venture, we are unaware of how they utilized it, but they were impressed by the data collected.



Hypertension/Blood Pressure (Project I.M.P.A.C.T.)

Brief description of project (health issue, objectives of program, etc.)

NBCI, working with Dr. James Powell of Project I.M.P.A.C.T. and the National Medical Association participated in a clinical trials program to measure the rates of African-Americans and the role of stress in their lives.

Number of people who participated in the educational series

4,558

Number of people who screened for the research study

3,700

Number of people who enrolled in the research study

558

Heart Disease (Project I.M.P.A.C.T.)

Brief description of project (health issue, objectives of program, etc.)

The purpose of the project was to see if African-American heart disease patients experienced a lifestyle change as a result of their heart disease.

Number of people who participated in the educational series

15,726

Number of people who screened for the research study

The number of people screened was low, **400**

Number of people who enrolled in the research study

72 people enrolled in the research study.

Type II Diabetes (Project I.M.P.A.C.T.)

Brief description of project (health issue, objectives of program, etc.)

NBCI, working with Dr. James Powell of Project I.M.P.A.C.T. and the National Medical Association participated in a clinical trials program look at the drug compliance and the number of doctor visits of African-American adults with type II diabetes.

Number of people who participated in the educational series

Over 7,000

Number of people who screened for the research study

2,633

Number of people who enrolled in the research study

358

Multiple Myeloma (Novartis)

Brief description of project (health issue, objectives of program, etc.)

Nationwide comprehensive health awareness initiative of Multiple Myeloma.

Number of people who participated in the educational series

Over 1 million, in an online web-based campaign.

Number of people who screened for the research study

We are not certain of the number; there was an 18.0% increase in screening among African-American men over 60.

Number of people who enrolled in the research study

We are unaware of the number, but were told by the five Myeloma associations that they experienced a 20% increase concerning drug therapy and other related information.

Supporting Documents

Category	Bronze Anvil Awards – 9A. Websites External
Client	National Black Church Initiative, Novartis Pharmaceuticals Corp.
Agency	Ruder Finn
Program Title	To Stay in the Game, Maintain Your Frame
Budget	\$415,000

Planning/Objectives:

Churches have always played an integral role in African American history. Today, churches are continuing in this tradition by remaining dedicated to causes impacting the African American community, including health issues such as multiple myeloma, a little known disease that disproportionately impacts this population.

Multiple myeloma is an incurable blood cancer of the plasma cells that can lead to bone complications including pain and fractures. In the United States, an estimated 70,000 Americans are currently living with the disease and African Americans are twice as likely to be diagnosed as Caucasians.

Men are also more likely to have multiple myeloma than women and it is more common among the elderly. In 2011, Novartis Pharmaceuticals Corporation (NPC) retained Ruder Finn (RF) to identify a partner in the African American community to support an awareness program on multiple myeloma. RF recognized the power of the church within this community and identified the National Black Church Initiative (NBCI) as a partner in a new campaign centered around an online resource designed to educate African Americans about multiple myeloma, the importance of maintaining bone health and the need for doctor-patient dialogue about how to effectively manage bone complications and become active participants in their health.

Strategic Insights/Creativity: Primary research provided by the NBCI revealed that:

- One of the issues regarding African American health is that many organizations implementing programs have little experience reaching out to the African American community. In order for the community to become informed, it is important that African Americans receive information that culturally resonates with them and is dispersed through an appropriate communication venue. Churches are seen as one of these venues, as they are a valuable resource from which many African Americans turn to receive important updates relevant to the community. The NBCI saw the need for faith-based communications to address health disparities among African Americans and created the Health Emergency Declaration (HED) initiative. The goal of HED is to develop innovative programs aimed at providing critical wellness information to African Americans and church members. In addition, there were limited tools readily accessible to African Americans regarding multiple myeloma and how to effectively manage bone complications. Therefore, there was a direct need to fill this educational gap.
- Many African American men avoid going to their doctor for checkups because they find the visits stressful and often unhelpful. Health information needs to be relayed to them in an easy to digest and understandable manner, and they need to be reminded of the importance of proactive health management and keeping open communications with their doctors.

Based on the above insights, the NBCI, NPC and RF realized that in order to reach African Americans with education messages on multiple myeloma, especially those most at risk -- elderly African American men -- a comprehensive disease awareness resource needed to be created, as part of the NBCI's HED.

Execution: RF, on behalf of NPC, worked very closely with the NBCI to support their development of a multiple myeloma disease awareness microsite, *To Stay in the Game, Maintain Your Frame* (www.MaintainYourFrame.com), which is housed on the NBCI's website. RF collaborated with both NBCI clergy and medical advisors to carefully guide the development of the website content to ensure it would resonate with the African American community. The website offers multiple myeloma patient education materials and tips to promote bone health, highlighting the importance of speaking regularly with their physician about bone health. The website features five original short videos demonstrating how multiple myeloma patients can perform simple activities in their daily lives that may help reduce the risk of falls and other skeletal injuries. The videos are narrated by an African American oncologist and feature senior professional leaders of the NBCI Health HED.

Evaluation: The 2011 phase of the campaign was successful in meeting its original objectives:

- Opened up a critical dialogue about multiple myeloma and the need for doctor-patient dialogue among African Americans in a culturally-appropriate way via a new online resource; provided educational information and interactive videos with easy guidance on how to prevent falls to the African American community; information featured on the website was disseminated to the NBCI's coalition of 34,000 churches nationwide, spanning 15 denominations and representing 15.7 million African Americans.
- Direct feedback from NBCI church members revealed they found the website and videos to be very informative and helpful; many also stated they would share the website information with their friends and family.

In 2012, to broaden access to the website's educational materials, key cancer centers, patient advocacy organizations and African American organizations are being informed about this program. Responses thus far have been extremely positive and many groups have expressed interest in sharing the website resource with their constituents (e.g., Multiple Myeloma Research Foundation, the Patient Advocate Foundation, and Cancer Center at the University of Pennsylvania).

Supporting documents

[*http://www.naltblackchurch.com/health/multiple-myeloma.html*](http://www.naltblackchurch.com/health/multiple-myeloma.html)

Multiple Myeloma and Cancer Educational Materials

[*http://www.naltblackchurch.com/health/mm-factsheets.html*](http://www.naltblackchurch.com/health/mm-factsheets.html)

Additional Resources Section

[*http://www.naltblackchurch.com/health/mm-resources.html*](http://www.naltblackchurch.com/health/mm-resources.html)

The Health Sermon is part of our commitment to providing health information to our members.

[*http://www.naltblackchurch.com/health/pdf/mm-healthsermon.pdf \[pdf 106kb\]*](http://www.naltblackchurch.com/health/pdf/mm-healthsermon.pdf)

The International Myeloma Foundation (IMF) conducted a study to determine the underlying reasons for the increased risk of myeloma in certain races and in family members.

[*http://survey.myeloma.org/*](http://survey.myeloma.org/)

To Stay in the Game, Maintain Your Frame - 2011 Results Report

[*http://www.naltblackchurch.com/health/media/sitg-results01042011.ppt*](http://www.naltblackchurch.com/health/media/sitg-results01042011.ppt)

COPD (Boehringer Ingelheim)

Brief description of project (health issue, objectives of program, etc.)

This was a non-brand awareness and screening campaign.

Number of people who participated in the educational series

We confidently approximate that over 100,000 NBCI members were impacted.

Number of people who screened for the research study

Health screenings were conducted at over 50 churches, impacting over 30,000 congregants.

Number of people who enrolled in the research study

COPD Foundation recorded a 35% increase concerning drug therapy and other related information from NBCI members.

Supporting documentation

[*http://www.naltblackchurch.com/health/copd/copd-curriculum.ppt*](http://www.naltblackchurch.com/health/copd/copd-curriculum.ppt)

[*http://www.naltblackchurch.com/health/pdf/copddemo-project.pdf*](http://www.naltblackchurch.com/health/pdf/copddemo-project.pdf)



Autism

Brief description of project (health issue, objectives of program, etc.)

This was an awareness and clinical trial program. We went to five cities, Washington, DC, New York, NY, Cleveland, OH, Charleston, SC and Raleigh/Durham, NC

Number of people who participated in the educational series

The number of people who received information and literature was 27,552.

Number of people who screened for the research study

Over 700 children.

Number of people who enrolled in the research study

164 children.

Supporting documents

Autism Clinical Trials – Connect Me

[*http://www.naltblackchurch.com/health/autism-speaks.html*](http://www.naltblackchurch.com/health/autism-speaks.html)

This is the page devoted to the Autism Speaks organization

[*http://www.naltblackchurch.com/health/autism-speaks.html*](http://www.naltblackchurch.com/health/autism-speaks.html)

Autism Speaks "Intervention Services" with options to locate screening.

[*http://www.naltblackchurch.com/health/intervention-services.html*](http://www.naltblackchurch.com/health/intervention-services.html)

Map and NBCI Churches

Here is a detailed map of NBCI Faith Commands and number of churches in each of the United States.



NBCI Faith Communities Demographics and Statistical Composition

NBCI has created a statistical analysis of its churches, locations and demographics

The South East Faith Command	16,830 Churches
The West Faith Command	8,502 Churches
The Mid-West Faith Command	3,047 Churches
South West Faith Command	3,265 Churches
Western Faith Command	2,356 Churches

				GENDER %		RACE %	
	FAITH COMMAND	NO. OF CHURCHES	AGE RANGE	MALE	FEMALE	BLACK	HISPANIC
SOUTHEAST FAITH COMMAND -- 16,830 Churches ATLANTA, GA							
A	FLORIDA	618					
	<i>Tallahassee</i>	268	30-75	36	64	100	
	<i>Miami</i>	280	30-80	35	65	100	
	<i>West Palm Beach</i>	12	34-80	39	61	100	
	<i>Fort Lauderdale</i>	58	45-80	35	65	100	
	Georgia	2659					
	<i>Atlanta</i>	2560	28-85	45	55	100	
	<i>Savannah</i>	99	39-85	34	66	100	
B	Louisiana	956					
	<i>Baton Rouge</i>	600	45-85	34	66	100	
	<i>New Orleans</i>	356	45-85	35	65	100	
	Alabama	1439					
	<i>Birmingham</i>	780	28-85	45	55	100	
	<i>Montgomery</i>	656	32-85	45	55	100	
C	Arkansas	86					
	<i>Little Rock</i>	86	35-85	40	60	100	
	Tennessee	2224					
	<i>Memphis</i>	860	28-85	45	55	100	
	<i>Nashville</i>	906	28-85	45	55	100	
	<i>Chattanooga</i>	458	28-85	45	55	100	
D	Kentucky	560					
	<i>Louisville</i>	362	33-85	38	62	100	
	<i>Lexington</i>	198	35-85	38	62	100	
	Mississippi	1807					
	<i>Jackson</i>	1807	24-85	41	59	100	
E	North Carolina	1749					
	<i>Charlotte</i>	450	25-85	45	55	100	
	<i>Winston Salem</i>	346	25-85	45	55	100	
	<i>Raleigh</i>	462	25-85	45	55	100	
	<i>Durham</i>	241	25-85	45	55	100	
	<i>Greensboro</i>	250	25-85	45	55	100	
	South Carolina	1520					
	<i>Columbia</i>	838	35-85	40	60	100	
<i>Charleston</i>	682	35-85	40	60	100		

				GENDER %		RACE %		
	FAITH COMMAND	NO. OF CHURCHES	AGE RANGE	MALE	FEMALE	BLACK	HISPANIC	
F	Washington, DC	1609	45-85	40	60	100		
	Virginia <i>Richmond</i> <i>Northern-Virginia</i>	1606 606 1000	35-85 35-85	45 33	55 67	100 100		
NORTHEAST FAITH COMMAND -- 8502 Churches NEW YORK								
A	New York <i>New York City</i> <i>Albany</i>	2836 2680 156	47-85 38-85	32 50	68 50	100 100		
	New Jersey <i>Newark</i> <i>Trenton</i>	1372 680 692	47-85 47-85	31 31	69 69	100 100		
B	Pennsylvania <i>Philadelphia</i> <i>Pittsburgh</i>	1501 1001 500	38-85 43-85	35 35	65 65	100 100		
C	Maryland <i>Baltimore</i> <i>Prince George's County</i>	1993 1008 985	28-85 28-85	45 45	55 55	100 100		
	D Massachusetts <i>Boston</i>	400 400	47-85	68	100	100		
	Connecticut <i>Hartford</i> <i>New Haven</i>	400 200 200	38-85 38-85	38 38	62 62	100 100		
	MIDWEST FAITH COMMAND -- 3047 Churches CHICAGO							
A	Ohio <i>Columbus</i> <i>Cleveland</i> <i>Dayton</i> <i>Cincinnati</i>	953 162 289 316 186	47-85 47-85 47-85 47-85	32 32 32 32	68 68 68 68	100 100 100 100		
	B Illinois <i>Chicago</i>	800 800	27-85	40	60	100		
	C	Kansas <i>Kansas City</i> <i>Topeka</i>	158 89 69	38-85 38-85	38 38	62 62	100 100	

				GENDER %		RACE %	
	FAITH COMMAND	NO. OF CHURCHES	AGE RANGE	MALE	FEMALE	BLACK	HISPANIC
C	Wisconsin <i>Milwaukee</i>	58 58	38-85	38	62	100	
D	Michigan <i>Detroit</i>	969 969	38-85	38	62	100	
E	Indiana <i>Indianapolis</i>	109 109	38-85	38	62	100	
SOUTHWEST FAITH COMMAND -- 3265 Churches DALLAS							
A	Texas <i>Dallas</i> <i>Houston</i>	3265 956 1206	26-85 26-85	48 48	52 52	100 100	
B	<i>Fort Worth</i> <i>San Antonio</i>	603 500	26-85 26-85	48 48	52 52	100 100	
WEST FAITH COMMAND -- 2356 Churches OAKLAND							
A	California <i>Oakland</i> <i>Los Angeles</i> <i>San Francisco</i>	2356 1356 700 300	41-85 41-85 48-85	33 33 32	67 67 68	100 100 100	
TOTAL NBCI CHURCHES 34,000							



The Benefits of Clinical Trials for African Americans

Praise the Lord Saints!

Mark 11:24 *“Therefore I tell you, whatever you ask for in prayer, believe that you have received it, and it will be yours.”*

This morning I would like to share with you some critical information about clinical trials. This health sermon is part of our church commitment of providing sound health information to our members under the National Black Church Initiative (NBCI) Health Emergency Declaration. We are required to provide two and a half hours of health information every week over the next seven years. Let the church say Amen!

Our scripture lesson is taken from

Good morning, I want to speak to you today about clinical trials. A clinical trial is a research study done by doctors. A treatment or a drug must be studied in clinical trials before it can be considered for approval by the US Food and Drug Administration (FDA). Once approved, the treatment or drug can be prescribed by doctors.

Education and awareness are key in getting African Americans to participate in clinical trials.

- To better educate patients, several safeguards were put into place. Every patient needs to sign a form, called an “informed consent” that gives the patient information about the study, the tests that will be performed, the possible benefits and risks and the patient’s rights, including the right to leave the study at any time. Patients who are a part of a clinical trial are given either the best treatment currently available OR a new and possibly more effective treatment.

***Jeremiah 17:14 - "Heal me, O LORD, and I shall be healed;
Save me, and I shall be saved, For You are my praise."***

- African-Americans make up only 5 percent of clinical-trial participants. Therefore, scientists who research different diseases and conditions don't know how these drugs or treatments work in the African American population. It is important for you and for the next generation that scientists learn how these clinical trial treatments work in the African American population.
- It is very important to speak to your doctor about clinical trials as an option for care. Sometimes there are clinical trials in the hospital or center where you are receiving treatment. Other times, you may need to travel somewhere to receive the clinical trial treatment. Many times, there is funding available for this.
- It is important to know that being treated in a clinical trial has enormous benefits. Patients in clinical trials receive either the best treatment currently available, or a new and possibly more effective treatment. Many clinical trials are randomized. These allow doctors to compare new treatments with treatments already used.
- The Leukemia & Lymphoma Society (LLS) wants to educate you about clinical trials as a treatment option to make you an informed patient. LLS exists to find cures and ensure access to the best available treatments for blood cancer patients. LLS is the world's largest voluntary health organization dedicated to funding blood cancer research, education and patient services. LLS has chapters throughout the country and in Canada.

You can call The Leukemia & Lymphoma Society's Information Specialists for more information about clinical trials for blood cancers, at 800-955-4572. Information Specialists are oncology professionals who can help cancer patients navigate the best route from diagnosis through treatment, clinical trials and survivorship. They will speak with you one-on-one about your individual situation.

We welcome your questions and inquiries on how to access a clinical trial if you have a blood cancer. Here is our website, email and telephone number.

Website: www.LLS.org/informationsspecialists

Email: infocenter@LLS.org

Telephone number: (800) 955- 4572



NBCI Corporate Capability

NBCI has the capability of reaching African American and Latino target populations with health literature and information per zip code anywhere in the United States where there are black churches

NBCI has the capability to recruit African America and Latino populations for clinical trails

NBCI has the capability to reach not only its 34,000 African American churches but also the balance of the 150,000 African American churches in the country. (We are about four months away from compiling a comprehensive directory of all black churches in the country)

NBCI has the capability of reaching all of its 34,000 churches by e-mail

NBCI has the capability to conduct health surveys

NBCI has more than 856,000 e-mails of its membership

NBCI is building a very strong online social media presence through Facebook, Twitter and Instagram

NBCI has the capability to create and develop effective online health e-mail blasts to its membership and the general public

NBCI is publishing a quarterly 11-page health oriented newspaper as a means of reaching its targeted population at a minimum of 100,000 copies up to 500,000 copies starting in September of 2014

NBCI health team has the capability to conduct newspaper, radio and television interviews for health promotion campaigns

NBCI has produced over 80 YouTube videos

NBCI has extensive graphic and publishing capabilities

NBCI has the ability to produce, edit and distribute health sermons to all of its churches

NBCI has the ability to disseminate, through a close working relationship with 10,000 National Black Religious Broadcasters, health promotion awareness campaigns over the radio and internet

NBCI has the capability to publish health editorial articles through 247 black newspapers

NBCI serves as a guest columnist for those 247 black newspapers

Great example of this is our To Stay in the Game, Maintain Your Fame, 2011 Results Report Novartis



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