



*A Faith-Based Strategy to Defeat Cancer in
the African American Community*

Introduction

We just wanted to state from the onset of this relationship that we have a single goal of finding a creative way to work successfully with the National Cancer Institute (NCI) so that you can reach your goals in the areas of research, clinical trials and programming. We clearly understand that the success of NCI is the success of all Americans, especially African Americans. The thoughts that we have set forth is what we believe is the most creative way of integrating NCI programming into NBCI's structure. The structure that we set forth will easily integrate the National Outreach Network, the Geographic Management of Cancer Health Disparities Program (GMaP) and the Partnerships to Advance Cancer Health Equity or PACHE Program.

We are excited about joining with the National Cancer Institute (NCI) in this exciting partnership. The strengths that both organizations bring to this initiative are enormous. NCI is our nation's leading researcher and innovator concerning cancer research, not only in this country but around the world. Its level of expertise in the area of cancer research, therapies and cures is at the zenith level.

The National Cancer Institute (NCI) is the federal government's principal agency for cancer research and training. NCI leads, conducts, and supports cancer research across the nation to advance scientific knowledge and help all people live longer, healthier lives.

As the leader of the cancer research enterprise, NCI manages a broad range of research, training, and health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients. These efforts extend across the entire country, meeting the needs of all demographics—rich and poor, urban and rural, and all racial/ethnic populations.

NBCI brings an enormous strength in terms of having one of the most effective community science-based initiatives in the country which incorporates the faith and the civil communities. NBCI has enormous assets in its arsenal through its 34,000 churches, 15.7 million members and over 20 years of experience. It also has a seasoned staff with a combined professional experience in critical areas such as:

- Research
- Community-based outreach
- Statistical gathering
- Critical distribution of health information
- Providing key health sermons
- The distribution of surveys
- The ability to identify target populations and provide them with up-to-date information concerning clinical trials, prevention and education around chronic health diseases.

With a major emphasis on cancer treatment and management

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 its members, congregants, Churches and the public. Our methodology is utilizing faith and sound health science.

NBCI'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.

The NBCI and the NCI's National Cancer Program Partnership represents enormous potential and opportunity to reduce racial and ethnic disparities in the variety of areas cited above. It is a partnership that can and will ensure that the all people, but particularly the most vulnerable are provided sustainable, culturally appropriate and clear language materials and timely information on cancer prevention, cancer education and cancer clinical trials.

Objectives

There are three objectives that we seek:

- 1) To bring to bear, through this enormous partnership, the reservoir of knowledge and resources pertaining to cancer prevention and management and to be able to translate that to every single member of NBCI congregations and the entire Black community.
- 2) To translate this critical science-based information in a way that average Americans can understand and act on it with some sense of urgency by changing their lifestyles, critical literature, early detection in screening, clinical trials and treatment of various cancers.
- 3) To create a level of trust between clinicians and African American faith communities across the country whereby we can garnish and obtain critical data through surveys and increase significantly clinical trial participation.

The National Black Church Initiative Science-Based Clinical Trials Methodology

NBCI Clinical Trial Education Awareness and Participation Program (CTEAPP)

NBCI's mission is to provide critical wellness information to all 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.

How We Envision the Partnership

The National Black Church Initiative envisions this partnership on both a global and micro level.

On the global level, we hope to interact with NCI leadership around critical programming consisting of but not limited to:

- Creation of two integrated NBCI websites that deal with the Black Church and Clinical Trials and African Americans and cancer
- Supporting the NCI Cancer Moonshot Initiative
- Supporting the NCI 21st Century Cures Act
- Supporting the NCI Director's special projects (with 250 Churches throughout the country)

There are five objectives in the global relationship that we hope to achieve:

1. Creation of two integrated NBCI websites that deal with the Black Church and Clinical Trials and African Americans and cancer:
 - Website (1): Black Church and Clinical Trials

Congregants will be trained on the use of 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 purpose of this site is to make the search extremely user friendly for people who may have a non-sophisticated approach to the internet by utilizing simplistic layouts, graphics, alphabets and numbers. In addition, it will be linked to clinicaltrial.gov.

- a) The website will be advertised to not only NBCI's 34,000 churches but also to the entire Black Church community consisting of 150,000 Black Churches.
- b) The website will be utilized as the anchor piece to NBCI's currently ongoing clinical trial program called the *ABC's of Clinical Trials: And What Are Their Benefits?* In addition, the site will be linked to the forthcoming Clinical Trial Education Awareness and Participation Program Lecture Series
- c) We will work with the technical staff of clinicaltrial.gov to ensure technological consistency and that the integrated links are active and working.
- d) This website will give us the ability to prioritize clinical trials that both NBCI clinicians and NCI clinicians deem as critical.
- e) The website will be set up with a feature to collect critical data in accordance with all government accepted regulations. In other words, the site will have the ability to participate in important clinical surveys concerning specific disease populations. We will do this in conjunction with NBCI Black Church Health Consumer Index Project (BCHCIS) www.naltblackchurch.com/health/bchcis.html

- Website (2): African Americans and cancer

Created to simplify the cancer related issues that may be specific to the African American community (i.e., genetically linked cancers, rare cancers that impact African Americans, etc.). It will highlight the following for users:

- a) Information on their particular cancer written in a language they can understand
- b) Links to other key websites related to their cancer and information on how to get in touch with those organizations like NCI and the American Cancer Society.
- c) Specific cancer associations like LLS, American Cancer Society, the Colon Cancer Alliance and other organizations that will be helpful as well as their websites and phone numbers
- c) List African American health resources in all geographic areas throughout the country like the National Medical Association
- d) List specialists, African American doctors as well as other doctors who are specialists in the area of cancer treatment and surgery
- e) Provide information on how they can access services from the National Cancer Institute and federal health clinics around the country
- f) Administer surveys to ease ability to participate in research conducted around the nation and beyond
- g) List clinical trials that are actively seeking individuals with certain types of cancer

Most importantly the website will serve as a guide for those who have insurance and those who do not have insurance and there will be a clear road map on how they can gain access to services. There will also be other critical information on social organizations such as the National Black Church Initiative and the services we offer in education and prevention. This user-friendly mechanism, through both the Black Church and Clinical Trials and African Americans and cancer websites will revolutionize how African Americans access information that would lead to participation.

2. Support NCI Cancer Moonshot Initiative

- The Cancer Moonshot to accelerate cancer research aims to make more therapies available to more patients, while also improving our ability to prevent cancer and detect it at an early stage.

3. Support NCI 21st Century Cures Act

- The Cures Act, or the 21st Century Cures Act legislation provides NIH with critical tools and resources to advance biomedical research across the spectrum, from foundational basic research studies to advanced clinical trials of promising new therapies.

Importantly, the Cures Act provides NIH with the flexibility and resources needed to accomplish its mission to improve the health of Americans. Most notably, the Cures Act implements measures to:

- Alleviate administrative burdens that can prolong the start of clinical trials
- Allow researchers to more easily attend scientific conferences where in-person collaboration can often lead to scientific breakthroughs
- Enhance data sharing among NIH-supported researchers
- Improve privacy protections for research volunteers
- Encourage inclusion of diverse populations represented in clinical research
- Open up new NIH funding opportunities for young investigators

4. The Director's Special Projects

NBCI will be supportive of the Director's special initiatives as a means of building our global relationship and trust while pushing forward with NCI in the same direction in building a solid partnership.

How NCI Centers Will Interact with NBCI Program and Staff

This is the concept of how we envision the micro relationship through an alliance with the 70 NCI Centers around the country.

The National Black Church Initiative through its 34,000 African American churches and 15.7 million members envision a robust and substantive relationship with NCI's 70 designated cancer Centers around the country. NBCI will provide those Centers with a variety of services including geo coding of our churches near each of the NCI Centers. Additional services may include but are not limited to the following:

- **Coordinate with NCI, 25 health educators, on how they can effectively impact NBCI church communities across the country and reach their NCI internal work objectives**

We will coordinate with the 25 NCI health educators to interact with our congregations throughout the country in a full-scale educational setting three times a year. We will also make available to those educators a support staff in coordinating community outreach, to the mini-congregations in their geographic/zip code areas. These 10 individuals will be separate from NBCI congregational volunteers. How that would work is simple, the NCI health educator will make a request, one of the ten volunteers per Center will contact that congregation or group of congregations on their behalf as well as each NBCI congregational volunteer in that geographical zip code to help them coordinate a response to the request of the NCI health educator.

This may be more than the three official contacts in a calendar year to establish ongoing relations.

- **Center Director Address to NBCI Churches**

Each of the 70 Center Directors, depending on their geographic location, will have an opportunity during a calendar year to address one of NBCI's congregations to illuminate their vision and priorities around cancer in their geographic area. Here is also an opportunity for him/her to be introduced to NBCI clergy leadership. That can consist of but is not limited to over 100 faith communities depending on the zip code. The coordination will be made by NBCI national staff.

- **Creation of a Press Release**

To denote the importance of the partnership between NBCI and NCI.

- **Provide two African American physicians who will help in explaining the objectives of the clinical trial to our target population around the issue of cancer**

NBCI will provide two African American physicians who will serve as technical assistance experts on this project to augment your excellent clinical education staff to help raise awareness of this disease and to help our members receive the latest scientific information. It is critical that your staff see those physicians to align cultural competency and appropriate strategies so

that our members can be comfortable and open to receiving the critical information that you and your staff will provide.

- **Recruitment for Clinical Trials**

NBCI will implement the principles around the Clinical Trial Education Awareness and Participation Program (CTEAPP) for the recruitment of clinical trials. These principles have been carefully evaluated to make sure that NBCI congregants are fully aware of both the risks and the benefits and that there is a clear emphasis on patient informed consent, education, and awareness of the objectives and purpose of the clinical trial. Dr. Owen Garrick will provide leadership in this area with the Center Directors and Principal Investigators.

- **Church and Pastor outreach (teleconference, email, in-person meetings)**

Creation and distribution of message points and a template email to each church Pastor explaining the significance of the NCI health clinics and how the church can best share this information to the congregation (to be developed in collaboration with NCI and approved in advance). NBCI staff will follow up by email, telephone and with in-person meetings with each of the pastors to ensure commitment to the project and follow-through. This contact will also help us trouble-shoot for any resistance and to learn of any questions they may have.

- **Health at a Glance church program insert**

Working with NCI on content and design, we will email each participating church a document to print and provide to members of the congregation. Our Health at a Glance insert is usually half the normal 8.5 x 11 paper size that has essential information on the disease, the symptoms and critical website and phone numbers so the individuals can have a chance to follow up. Use of a Health at a Glance program insert is a common practice with NBCI churches—we do this about 4-5 times a year—and we get an average 80% download rate every time. Again, we will be doing extensive follow-up by telephone and email to ensure follow through.

Here is a link to an example of Health at a Glance:

<http://www.naltblackchurch.com/health/pdf/myeloma-healthataglance.pdf>

- **Email Blasts**

We will create an email blast specifically designed to provide cancer information to congregants with a desire to participate in this study.

- **Web Page Creation with information on cancer**

This will be used as a link between NBCI's website and local Centers.

- **Congregational Volunteer Training**

These volunteers will make up the NBCI volunteer health core as outlined in our HED guidelines. We will activate some 10 congregational-based volunteers per Center in their area (as well as, at least 1 volunteer in 25 area churches) to make sure that this information gets to the targeted population.

- **ID of study participants**

Identification of potential study participants who desire to receive more information about the clinical trial which will lead to their participation.

- **Education**

Work with NCI Centers and their team in making available to them opportunities for education in our congregation.

- **Health Sermons**

To provide an opportunity for Dr. Lewis, Dr. Garrick (NBCI Medical Officers) and anyone recommended by NCI to talk to our congregations on cancer and the importance of informing one's family and friends about it.

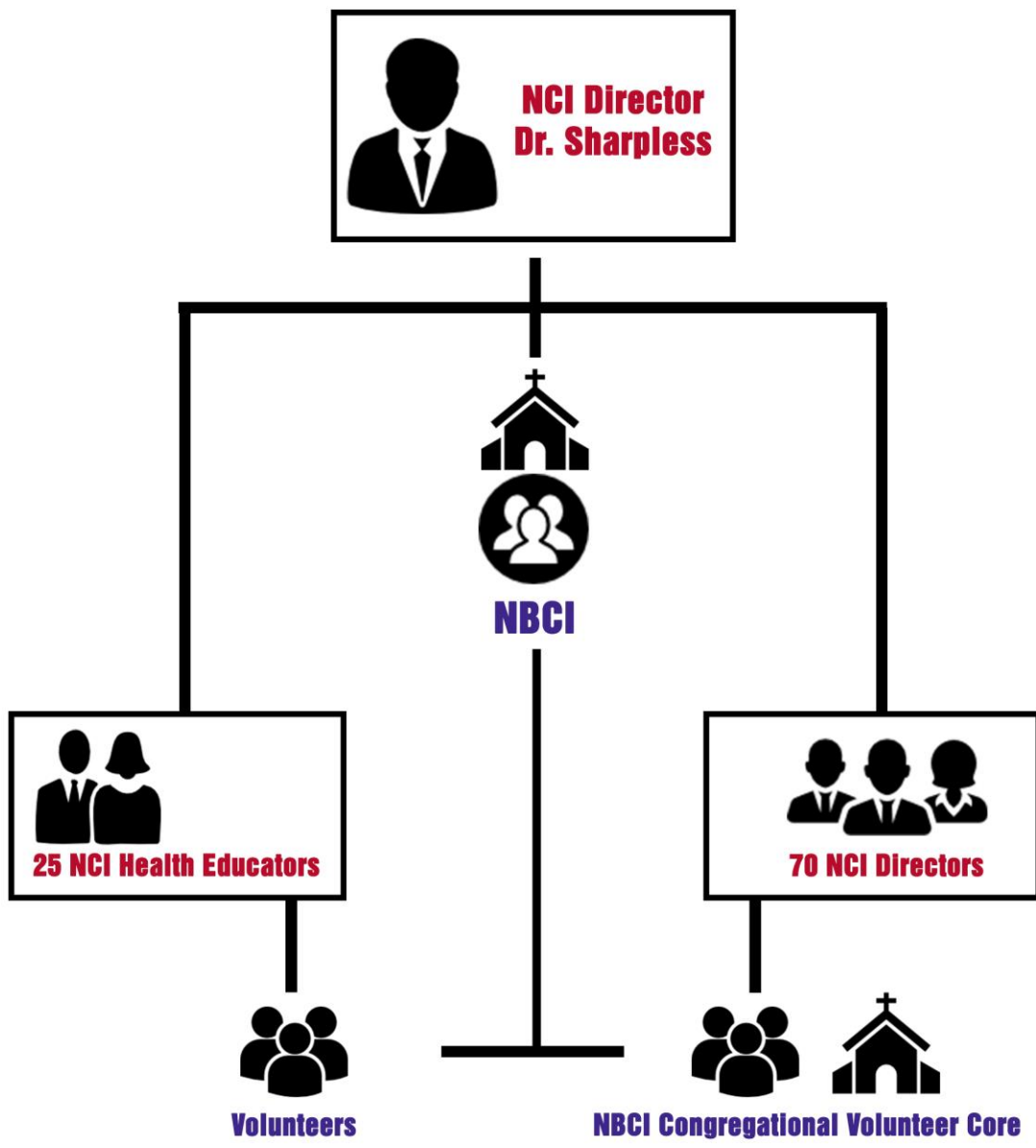
- **Literature distribution and follow up**

- **Local support**

NBCI will also provide technical assistance to all members in the identified sites. We will recruit from church membership, two site coordinators so any technical questions can be brought to them.

- **Follow up/feedback**

A follow-up email (created in collaboration with NCI) to get feedback from the Pastor on the receptivity of the sermon and literature. NCI will approve the content of the follow-up email and NBCI will compile responses to provide NCI with a written report.



Statistical Impact

The potential for sustainable impact is significant. Given NBCI's global as well as micro relationship with both NCI headquarters and the 70 designated NCI Centers.

The Director of the National Cancer Institute will be given an opportunity to address any congregation in NBCI's network in any zip code at any particular time regarding a national initiative which NBCI will be supportive of. This could mean that Director Sharpless can, over a 1-year period, address 4-5 of our prominent congregations in different geographic areas. The remarks will be recorded and shared through NBCI various social media and websites.

We are going to authorize over 250 congregations throughout the country who will be supportive of the Director's priorities going forward. They will be responsible for sharing the Director's goals and vision with other churches in their zip code throughout the country.

The NCI Center Directors

Each of the Center Directors will be given 10 volunteers each in addition to the 25 churches in their zip codes to help illuminate the vision they have set. This gives the Center Directors globally a base of over 700 volunteers plus in terms of churches, 1,750 churches. In addition, NBCI will provide an additional 250 churches to make an even 2,000 churches committed to NCI. The 250 churches will be national churches we will provide to the Director as a platform to getting critical priorities out on a national basis. This will be carefully coordinated with NCI communications staff.

The Goal

When you multiply the 2,000 congregations by the average Black Church of around 500 people, you get over the next 5 years, a pool of about 1,000,000 individuals. Given that pool of 1,000,000 through the apparatus we are setting up we will be able to utilize that pool in terms of recruitment for clinical trials, survey analysis, conduct awareness programs, provide critical education, and other special projects that the Director and Centers deem necessary.

This pool will also serve other needs as they arise to be supportive of both the Director's priorities and agenda and the 70 Center Director's goals as well.

NBCI NCI 5-Year Work Plan

Year 1

Introduction and education of NBCI NCI Partnership

Meeting of the NBCI/NCI stakeholders

Assessment of Special projects from NCI

Introduction to 70 designated NCI Centers

Press Release and social media messaging

Evaluation of Center needs

Content development for Health Note

Websites development

Year 2

Meeting of the NBCI/NCI stakeholders

Impact for African American and Latino families

Reviewing Center requests/meeting Centers needs

Training

10 volunteers per Center

25 partner churches

Clinical recruitment

Year 3

Meeting of the NBCI/NCI stakeholders

Education of Centers function

Full implementation of NBCI CTEAPP recruitment

Year 4

Full implementation of NBCI CTEAPP recruitment

Setting recruitment goals

Year 5

Full integration of NBCI/NCI system

