

Sickle Cell Disease Awareness and Education Strategy Development Workshop Report

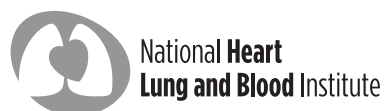


U.S. Department of Health and Human Services
National Institutes of Health
National Heart, Lung, and Blood Institute

Sickle Cell Disease Awareness and Education Strategy Development Workshop Report



U.S. Department of Health and Human Services
National Institutes of Health



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Background

The National Heart, Lung, and Blood Institute (NHLBI) has long been committed to developing and maintaining research efforts that improve the lives of people who have sickle cell disease (SCD). Scientific advances have led to effective approaches for the management and treatment of SCD and the prevention of complications. As a result, people who have SCD live longer and more productive lives than they did in the past. Consistent with goals described in its strategic plan, the NHLBI is reexamining and realigning its research program on SCD to embark on a revitalized research portfolio of basic, clinical, and translational research.

The NHLBI is currently developing evidence-based guidelines for the care of people who have SCD, which health care providers throughout the world can use. In addition, the NHLBI will launch a public awareness and education campaign to raise awareness of and bring nationwide attention to SCD. An essential component of this effort will be to educate providers and patients about SCD diagnosis and effective treatment options.

As part of the campaign's development, the NHLBI hosted a 2-day Strategy Development Workshop on September 2–3, 2009, in Bethesda, Maryland. The workshop brought together key stakeholders, including researchers, health care providers, advocacy organizations, patients, and other interested individuals, to help the NHLBI begin planning a national awareness and education effort on SCD.

Participants were charged with addressing key issues for a national campaign relating to target audiences, messages, strategies, and partnerships. Presentations covered the history of SCD and its

management, current and planned research in the field, historical barriers to and opportunities for planning a national awareness and education campaign, and an overview of Federal efforts related to SCD. In a moderated talk show format, SCD patients, family members, and health care providers shared their personal experiences of living with and managing SCD. A panel presented information about three successful NHLBI awareness and education campaigns.

Workshop Goals and Objectives

Goals

- Provide the NHLBI with recommendations for developing a national health awareness and education campaign to raise awareness about SCD and to bring nationwide attention to its diagnosis and treatment.
- Form a strong coalition of stakeholders and Federal Agencies to partner with the NHLBI in implementing the SCD awareness and education campaign.

Objectives

Provide the NHLBI with a set of comprehensive recommendations for a national health awareness and education campaign that:

- Identifies the key target audiences.
- Offers content for key messages appropriate to each target audience.
- Proposes program strategies, settings, and channels for delivering the messages that increase awareness and change behaviors, along with measures for assessing program effectiveness.
- Identifies potential partner organizations and people to work with the NHLBI in implementing and evaluating the campaign, and to expand the Institute's reach to desired audiences.



About Sickle Cell Disease

Sickle cell disease (SCD), also known as sickle cell anemia, is a serious disease in which the body makes an altered form of hemoglobin, the protein in red blood cells that carries oxygen throughout the body. This genetic alteration causes the body to produce abnormal sickle- or crescent-shaped red blood cells.

Unlike normal red cells that pass smoothly through the blood vessels, sickle cells are stiff and sticky and tend to form clumps that get stuck in the blood vessels and obstruct blood flow. The result is episodes of extreme pain (“crises”), as well as chronic damage to vital organs.

SCD is an inherited disease. People who have the disease inherit two copies of the sickle cell gene—one from each parent. If a person inherits only one copy of the sickle cell gene (from one parent), he or she will have sickle cell trait. Sickle cell trait is different from SCD. People who have sickle cell trait do not have the disease, but they have one of the genes that cause it. Like people who have SCD, people who have sickle cell trait can pass the gene to their children.

SCD is most common in people whose families come from Africa, South or Central America (especially Panama), Caribbean islands, Mediterranean countries (such as Turkey, Greece, and Italy), India, and Saudi Arabia. In the United States, it is estimated that SCD affects about 70,000 to 100,000 people, primarily African Americans. The disease occurs in about 1 out of every 500 African American births.

A common misconception is that SCD is solely an African American disease, but it also affects Hispanic Americans and other emerging populations in this country. The disease occurs in 1 out of every 36,000 Hispanic American births.¹

Exhibit 1. Normal and Sickled Red Blood Cells

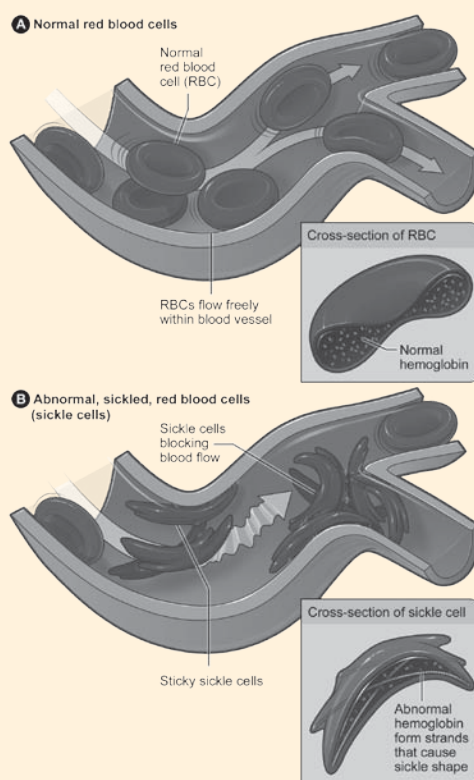


Figure A shows normal red blood cells flowing freely in a blood vessel. The inset image shows a cross-section of a normal red blood cell with normal hemoglobin.

Figure B shows abnormal, sickled red blood cells clumping and blocking blood flow in a blood vessel. (Other cells also may play a role in this clumping process.) The inset image shows a cross-section of a sickle cell with abnormal hemoglobin.

¹ National Heart, Lung, and Blood Institute. (2008). Sickle cell anemia. *Diseases and Conditions Index*. Retrieved from http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA_WhoIsAtRisk.html

About 2 million Americans have sickle cell trait.² This condition occurs in about 1 in 12,³ or 8 percent, of African Americans.^{4 5}

The severity of SCD varies from person to person. Some people who have the disease have chronic pain and/or fatigue. Many people who have SCD face a shortened life expectancy and a host of recurring, debilitating, and expensive health problems.⁶ The effects of sickle cell crises on different parts of the body can cause a number of complications, including infections and organ damage.

Two of the organs most susceptible to damage are the brain and the lungs. Strokes and a life-threatening respiratory problem known as acute chest syndrome are frequent complications for people who have SCD. The disease also damages the spleen at a very early age, which impairs the body's immune system and makes young children

extremely vulnerable to overwhelming bacterial infections.

SCD has no widely available cure, although blood and marrow stem cell transplants or gene therapy may offer a cure in a small number of cases. There are treatments for the symptoms and complications of the disease. Over the past 100 years, doctors have learned a great deal about SCD. They know its causes, how it affects the body, and how to treat many of its complications. Research is ongoing to learn more about SCD and to find new treatments for the disease.

With proper care and treatment, many people who have SCD can have improved quality of life and reasonable health much of the time. Due to improved treatment and care, people who have SCD are now living into their forties or fifties, or longer.

² National Heart, Lung, and Blood Institute. (1996). *Facts about sickle cell anemia* (p. 2) (NIH Publication No. 96-4057). Bethesda, MD: U.S. Department of Health and Human Services. Retrieved from http://www.nhlbi.nih.gov/health/public/blood/sickle/sca_fact.pdf

³ National Heart, Lung, and Blood Institute. (1996). *Facts about sickle cell anemia* (p. 2) (NIH Publication No. 96-4057). Bethesda, MD: U.S. Department of Health and Human Services. Retrieved from http://www.nhlbi.nih.gov/health/public/blood/sickle/sca_fact.pdf

⁴ National Heart, Lung, and Blood Institute. (n.d.). *Pulmonary and vascular medicine branch*. Retrieved from <http://dir.nhlbi.nih.gov/labs/pvmb/research-goals.asp>

⁵ Gladwin, M. T., & Vichinsky, E. (2008, November 20). Pulmonary complications of sickle cell disease. *New England Journal of Medicine*, 359(21), 2254–2265. Retrieved from <http://content.nejm.org/cgi/content/full/359/21/2254>

⁶ National Heart, Lung, and Blood Institute. (2002). *Sickle cell research for treatment and cure* (pp. 3–4) (NIH Publication No. 02-5214). Bethesda, MD: U.S. Department of Health and Human Services. Retrieved from <http://www.nhlbi.nih.gov/resources/docs/scd30/scd30.pdf>

Sickle Cell Disease Research History

In 1971, President Richard Nixon made research on sickle cell disease (SCD) a national priority. On May 16, 1972, the National Sickle Cell Anemia Control Act was signed into law. It provided for the establishment of voluntary sickle cell anemia screening and counseling programs, information and education programs for health professionals and the public, and research training in the diagnosis, treatment, and control of sickle cell anemia.

Shortly after the act was passed, the National Sickle Cell Disease Program was established, and the National Heart, Lung, and Blood Institute (NHLBI) was tasked with developing and supporting a program of research in SCD.

Since that time, the NHLBI has committed more than \$1 billion to research on SCD. The Institute supports an extensive research program to improve understanding of the pathophysiology of SCD and to identify effective approaches for its management and treatment and for prevention of complications.

Areas of current interest include genetic influences on disease manifestations, regulation of hemoglobin synthesis, development of drugs to increase fetal hemoglobin production, transplantation of blood-forming stem cells, gene therapy, and development of animal models for preclinical studies. The NHLBI supports this research through investigator-initiated projects and special initiatives.⁷

This public investment in SCD research has yielded significant returns, ranging from understanding fundamental biological and pathological processes to translating basic discoveries and clinical observations into clinical applications. Some examples of clinical benefits and research discoveries include:

- The life expectancy of SCD patients doubled between 1972 and 2002.
- Prophylactic penicillin given to SCD patients from birth to 5 years of age significantly reduced sepsis and mortality.
- Transcranial Doppler (TCD) screening identified children at increased risk for stroke.
- Periodic blood transfusions helped prevent first-time and recurrent stroke in children who had SCD and were at high risk for stroke.
- Hydroxyurea therapy in adults who had SCD resulted in a 50 percent reduction of the frequency of pain, acute chest syndrome, hospitalizations for painful symptoms, and units of blood transfused.
- Allogeneic bone marrow transplants were shown to cure the clinical symptoms of SCD.

Despite significant clinical returns, a critical need still exists for further research on SCD. This need is summarized in the conclusions of the conference statement for the February 2008 National Institutes of Health Consensus Development Conference on Hydroxyurea Treatment for Sickle Cell Disease:

“The burden of suffering is tremendous among many patients who have sickle cell disease. These patients experience disease-related pain on many days of their lives and usually do not seek medical attention until their symptoms

⁷ National Heart, Lung, and Blood Institute. (2008). *Report of the National Heart, Lung, and Blood Advisory Council Subcommittee Review of the NHLBI Sickle Cell Disease Program*. Retrieved from http://www.nhlbi.nih.gov/resources/docs/scd_program.htm

are overwhelming. They often attempt to treat themselves and thus do not always come to the attention of the healthcare system. Obtaining optimal care for patients who have sickle cell disease is challenging. Many patients are not in a coordinated program aimed at prevention of long-term complications and acute pain crises. They rely heavily on emergency and acute care facilities for pain control.

“Obtaining specialty care can be a significant challenge as the number of health professionals trained to treat the disease is limited and the number of professionals specializing in the treatment of this disease is decreasing. The likelihood that patients who have sickle cell disease have a principal physician is low. Transitioning from pediatric care to adult care poses particular challenges. Many children rely on public insurance for their care. Gaps in coverage occur, leading to gaps in care.

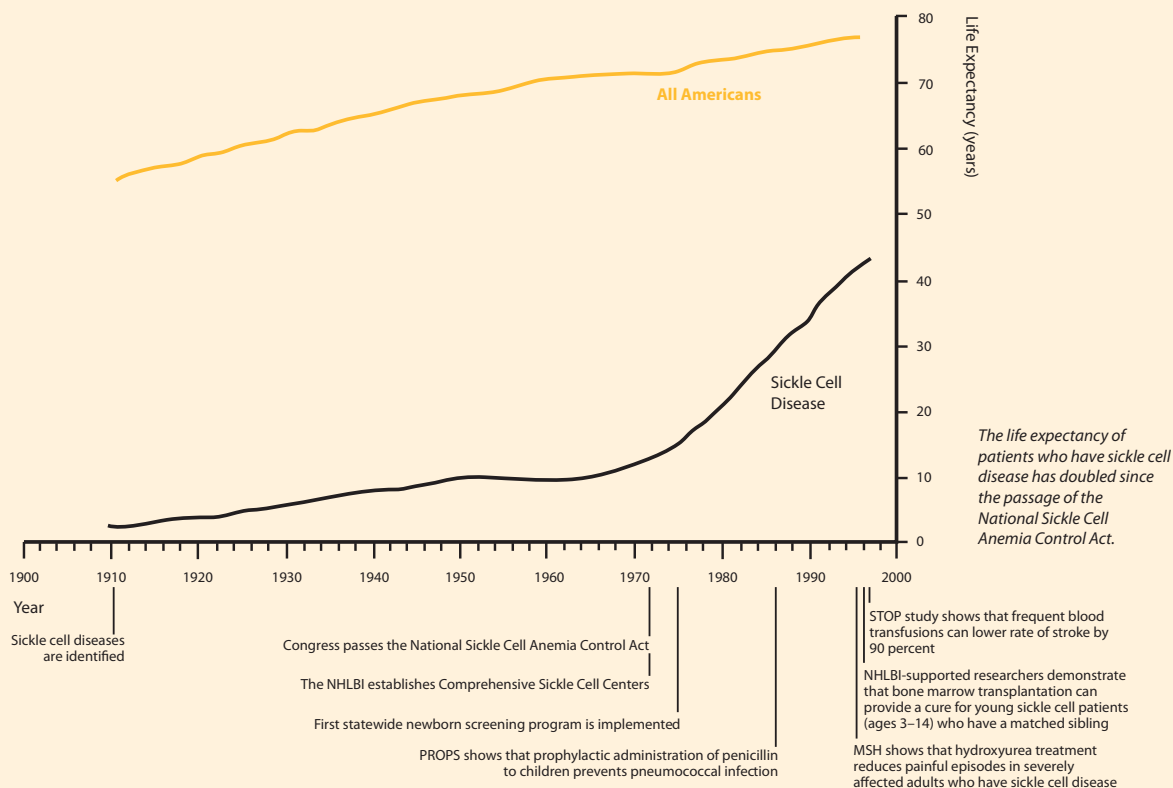
Exhibit 2. Selected Examples of Research

NIH-Initiated Research	Investigator-Initiated Research
<ul style="list-style-type: none"> ■ Sickle Cell Disease Clinical Research Network—initiated in fiscal year (FY) 2006 to facilitate translation of results from basic studies and phase I/II clinical trials into phase III trials in patients who have SCD; funding continues through FY 2010. ■ Phase II/III Trial of Sildenafil for Sickle Cell Disease-Associated Pulmonary Hypertension—initiated in FY 2006 as a complement to and extension of an NHLBI intramural trial to test the effects of sildenafil therapy on exercise capacity and elevated pulmonary artery pressure in SCD patients who have pulmonary hypertension. This trial was stopped in July 2009 due to safety concerns. In an interim review of safety data, researchers found that, compared to participants on placebo, participants taking sildenafil were more likely to have serious medical problems, including sickle cell crises. ■ Pediatric Hydroxyurea Phase III Clinical Trial (BABY HUG)—initiated in FY 2000 to assess the effectiveness of hydroxyurea in preventing chronic organ damage in young children who have SCD; funding continues through FY 2010. ■ Comprehensive Sickle Cell Centers—initiated in 1972 to support multidisciplinary research and expedite development and application of new knowledge for improved diagnosis and treatment of SCD; 10 centers were funded through FY 2007. 	<ul style="list-style-type: none"> ■ Stroke With Transfusions Changing to Hydroxyurea (SWITCH)—initiated in FY 2005 to compare standard therapy (transfusions and iron chelation) with alternative therapy (hydroxyurea and phlebotomy) for the prevention of secondary stroke and management of iron overload in children who have sickle cell anemia. ■ Stroke Prevention in Sickle Cell Anemia (STOP)—initiated in FY 1994 to determine whether periodic blood transfusions were more effective at preventing stroke than standard supportive care. ■ Sibling Donor Cord Blood Banking and Transplantation—initiated in FY 2001 to collect cord blood from sibling donors in families with children who have SCD or thalassemia with the intent of future transplantation. ■ Stroke Prevention in Sickle Cell Anemia (STOP 2)—initiated in FY 2000 to determine whether blood transfusions must continue or could be stopped and when.

“No population-based registries exist that provide good estimates of the number of people who have sickle cell disease. Surveys indicate that a large proportion of patients who have sickle cell disease are poor and from underserved communities. Most U.S. patients who have sickle cell disease are ethnic minorities. For many, the limited resources and lack of culturally competent care by experienced clinicians set the stage for suboptimal care.

“The best way to achieve optimal care for patients who have sickle cell disease, including preventive care, is for the patients to be treated in clinics specializing in the care of this disease. All sickle cell patients who have sickle cell disease should have a principal healthcare provider, and that provider, if not a hematologist, should be in frequent consultation with one.”⁸

Exhibit 3. Increases in Life Expectancy of Patients Who Have Sickle Cell Disease



Source: National Heart, Lung, and Blood Institute. (2002). *Sickle cell research for treatment and cure* (p. 15) (NIH Publication No. 02-5214). Bethesda, MD: U.S. Department of Health and Human Services.

⁸ National Institutes of Health. (2008). *NIH Consensus Development Conference: Hydroxyurea treatment for sickle cell disease. Final statement*. Retrieved from <http://consensus.nih.gov/2008/sicklecellstatement.htm>

Strategy Development Workshop Overview

The National Heart, Lung, and Blood Institute (NHLBI) convened a 2-day workshop in September 2009 to elicit recommendations from sickle cell disease (SCD) stakeholders for the development of a national awareness and education campaign. The NHLBI charged participants with addressing a number of key questions that would help inform the SCD campaign. These questions concerned target audiences, messages, communication strategies, and partnerships.

On the first day of the workshop, the NHLBI Director, Dr. Elizabeth G. Nabel, reviewed the history of SCD and past and current NHLBI research efforts. Speakers then addressed the meeting's call to action and historical barriers to and opportunities for creating a national campaign. They also provided an overview of other SCD education and outreach efforts. During a moderated talk show, several people living with SCD, a family member caring for children who have SCD, and clinicians providing care for SCD patients shared their personal experiences of living with and managing the disease.

A panel presentation informed the audience about the health communication process used in three successful NHLBI awareness and education campaigns—focusing on women's heart health, chronic obstructive pulmonary disease (COPD), and peripheral arterial disease (P.A.D.)—and the critical role of formative research in campaign design. Finally, an overview of existing SCD campaigns and other major educational efforts was presented. Following the presentations, participants broke into five small working groups

to address two key questions related to target audiences and campaign messages.

Presentations on the second day of the workshop covered an overview of the NHLBI's SCD research efforts in conjunction with the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA). Following these presentations, attendees again broke into small working groups to consider two final key questions pertaining to strategies and settings for message delivery and potential partners. In closing, Dr. W. Keith Hoots, Director of the NHLBI Division of Blood Diseases and Resources, summarized workshop activities and outlined the NHLBI's next steps for developing and implementing a national awareness and education effort.

Charge to Workshop Participants: Small Group Sessions

Participants were asked to consider the following questions and make related recommendations for developing a comprehensive campaign strategy.

- 1. Who are the key target audiences for the campaign?** The NHLBI sought to determine the audiences most in need of information and education, and those for whom outreach efforts could have the greatest effect. Participants were asked to consider any and all audiences and subsets of audiences, both public and professional.
- 2. What are the most significant messages for each target audience identified?** The NHLBI sought input on the focus of a national effort. Participants were asked to recommend whether the campaign should primarily have an awareness or education focus. Based on the recommended focus, participants were asked to propose the most significant messages needed for each target audience identified.

3. **What national strategies, community settings, and channels should the NHLBI develop for a national awareness and education campaign?** The NHLBI sought recommendations on strategies and communication channels for effectively disseminating the campaign's key messages and reaching the target audience(s).
4. **Which organizations would make the best potential partners for helping the NHLBI implement, sustain, and evaluate the campaign?** Partner organizations can help the NHLBI vastly expand its reach to the target audience(s). These organizations also can serve as trusted intermediaries for the dissemination and delivery of messages and materials to desired audiences. Workshop participants were asked to identify organizations that might contribute to the implementation of the SCD campaign.

Workshop Recommendations

Meeting participants enthusiastically embraced their charge to develop priority recommendations for creating a national SCD awareness and

education campaign. As they worked in small groups, they were able to make broad recommendations about target audiences, messages, implementation strategies, and partnerships. Although no single target audience emerged as a priority, the following three audiences were deemed essential: people who have SCD and their families, the general public, and health care providers.

Other general recommendations stemming from small-group discussions included the following:

- Raise awareness among affected populations about treatment and management options.
- Raise awareness among targeted segments of the general public about SCD, sickle cell trait, and their implications.
- Encourage people affected by SCD to become empowered about their own health and seek appropriate medical care.
- Educate primary health care providers about the management of and new standards of care for patients of all ages who have SCD.

Workshop Presentation Summaries

Presentations at the September 2009 workshop covered past, current, and future plans for Federal programs and research related to sickle cell disease (SCD), perspectives from people affected by SCD and providers working with SCD patients, and an overview of other National Heart, Lung, and Blood Institute awareness and education efforts. These presentations were designed to set the stage for deliberations that would take place in the small working group sessions.

Sections that follow provide summaries of content from the workshop's plenary sessions.

September 2, 2009

Welcome and Introduction

Elizabeth G. Nabel, M.D., Director, National Heart, Lung, and Blood Institute

The National Heart, Lung, and Blood Institute (NHLBI) believes in the importance of national education campaigns and has a history of measurably successful campaigns on topics such as heart health, asthma, and chronic obstructive pulmonary disease (COPD). This workshop serves as a milestone and starting place for development of a dynamic and effective sickle cell disease (SCD) awareness and education effort.

SCD is an extremely serious, chronic disease that affects people in the United States and throughout the world. The disease is especially prevalent in African American, Central and South American, Mediterranean, and Saudi Arabian populations. Although considered rare, it is estimated that SCD affects 70,000 to 100,000 people in the

United States, mainly African Americans. SCD occurs in approximately 1 out of every 500 African American births and 1 out of every 36,000 Hispanic American births. In addition, about 2 million people in the United States have sickle cell trait and can pass the sickle cell gene to their offspring.

“Sickle cell has a profound impact, not just on the patient, but on the whole family dynamic.”

—Stephanie Davis, M.D.

Although SCD is known to have existed earlier, Chicago cardiologist and professor of medicine James B. Herrick first noted the cell irregularity in his research in 1910. In 1949, Dr. Linus Pauling and colleagues showed that SCD results from a hemoglobin molecule abnormality and coined the term “molecular disease” to describe SCD. By the 1970s, management of the disease had grown to include blood transfusions, fluid management, and analgesic therapy. In 1972, under the National Sickle Cell Anemia Control Act, the National Institutes of Health (NIH) began SCD research studies. Findings from these studies led to a dramatic increase in life expectancy for people who had SCD. Since then, key research milestones have included:

- **1982:** Newborn screening was established in three U.S. States.
- **1983:** Efficacy of oral penicillin and confirmation of the importance of early diagnosis and treatment were demonstrated.
- **1991:** Compelling results were demonstrated from a multisite study on treatment with hydroxyurea.

- **1995:** A stroke prevention study yielded strong evidence for the value of Doppler ultrasound in stroke prevention.
- **2000:** Use of ultrasound for stroke showed progress in reducing pain, increasing lifespan, and improving quality of life for people who have SCD.

Today, research has confirmed that hydroxyurea is a valuable treatment for adults. BABY HUG, a pediatric clinical trial for the use of hydroxyurea in babies, is just being completed; another, longer study is planned. In addition, the NHLBI currently is undertaking a major effort with the Centers for Disease Control and Prevention to develop and implement a registry and surveillance system in hemoglobinopathies (RuSH). RuSH will be a national data system with a surveillance component, a registry system, and a biospecimen repository that will provide data to describe the epidemiologic and clinical characteristics of people who have all genotypes of SCD, thalassemias, and other hemoglobinopathies. The first phase of the project will be to conduct pilot studies in five to six States to test specific data collection methods, procedures, and organizational structures. This phase also will determine the feasibility of implementing RuSH on a national level.

The development of SCD guidelines is one of several priority areas for the NHLBI. The NHLBI plans to communicate the guidelines to primary health care providers and the general public, people who have SCD or sickle cell trait, and their families, advocates, and the media. This workshop—the first step in this communication effort—will help the NHLBI identify key target audiences, messages, and implementation strategies at local, national, and international levels. The workshop also will help forge partnerships to help the Institute achieve (and measure) success.

A Call To Action

**Lanetta Jordan, M.D., M.P.H., M.S.P.H.,
Chief Medical Officer, Sickle Cell Disease
Association of America**

The Sickle Cell Disease Association of America (SCDAA) has been the leading nonprofit consumer organization focusing on sickle cell disease (SCD) since 1971. The SCDAA has worked for nearly four decades to develop a coordinated national approach and partner with community-based organizations to provide information and support to people affected by SCD and their families.

“Children need to be treated differently from adults; right now there is a huge disconnect between childhood and adult treatment for sickle cell disease.”

—Tiffany McCoy, SCD patient

SCD is considered an “orphan disease” (poorly publicized and not yet adopted by the medical research and funding communities) because it affects fewer than 200,000 people nationwide. Although the medical burden of orphan diseases is great, these diseases often are last to receive research funding.

Many historical barriers have made advancements in SCD management difficult. For example, although research shows that severe and painful episodes are characteristic of the disease, widespread implementation of pain management has not occurred. This has led to more emergency room visits and hospitalizations than should be necessary. Although ambulatory centers today handle a range of medical problems, few are equipped to

care for the medical needs of patients who have SCD. In fact, some SCD treatment centers have been closed. Childhood screening for SCD is now mandatory in all 50 States, but standards of care and prevention measures that could improve quality of life are lacking.

To advance and improve the management of SCD, it is necessary to address the complexities of navigating the health care system, resolve access issues, address health care disparities that exist at both the individual and institutional levels, and engage the disadvantaged.

“I’m only a patient when I’m in the doctor’s office, I’m really a whole person living an active life; I just happen to live with sickle cell disease.”

—Tiffany McCoy, SCD patient

This meeting’s call to action is to develop ideas for a public awareness and education campaign that will improve the lives of people who have SCD by:

- Establishing trust of patients and families in the health care system.
- Providing health information in useful, understandable language.
- Helping patients navigate the complexities of today’s health care system.
- Delivering powerful personal stories to people affected by SCD via speakers’ bureaus, town hall and other meetings, and all forms of media and social networking technologies.
- Creating better alliances among organizations.
- Encouraging patients to participate in the clinical trials process by explaining in simple terms what this process involves and why it is important to both individuals and the SCD community as a whole.

Measurable outcomes might include reducing complications from comorbidities, number of days in the hospital, and stigma attached to the disease. The National Heart, Lung, and Blood Institute has led the way for other successful national awareness and education efforts. Now is the time to focus awareness and education efforts on SCD.

Opportunities and Challenges for Sickle Cell Disease Awareness in the United States

Carlton Haywood, Jr., Ph.D., M.A., Assistant Professor of Medicine; Associate Faculty in Bioethics, Johns Hopkins University

Historically, numerous barriers have hindered national awareness about sickle cell disease (SCD). For example, one barrier is the low prevalence of SCD compared with many other health problems affecting the African American community, such as cardiovascular diseases, cancer, and diabetes. Yet SCD is the most common disease identified in newborn screenings, and people who have the disease may face a range of medical complications and a shortened life expectancy. Unlike cystic fibrosis, a similarly rare disease, SCD has never garnered the public support required for adequate research.

The understanding of SCD has changed dramatically over the years. In the past, the medical community lacked knowledge about SCD, and little could be done for people who had the disease. Today scientists know that SCD was the first molecular disease discovered and that its inheritance pattern is a classic case study in many biology/genetics classes. Currently, a variety of treatments and self-care practices are available for people who have SCD.

Although African Americans historically have been marginalized both politically and socially, progress has been made. Between 1959 and 1972,

a number of events converged to bring attention to SCD, including an *Ebony* magazine feature about the disease, a heightened awareness during the 1960s Civil Rights Movement of issues affecting the well-being of African Americans, President Nixon's February 1971 focus on cancer and SCD as national health priorities, and the May 1972 National Sickle Cell Anemia Control Act. As a result of this awareness, we learned:

- The potential ability to capture public attention through sharing the personal experiences of people who have SCD.
- The potential strength of making SCD a community-wide issue.
- The benefit of using a powerful/prestigious person (for example, the President) to help place SCD in the national consciousness.

Many challenges to SCD awareness still exist. For example, how to best address issues related to SCD and carrier status (people who have sickle cell trait) generates a long list of questions, such as:

- How are SCD and sickle cell trait defined?
- What is the significance of having sickle cell trait?
- Is sickle cell trait considered a disease or condition?
- What risks are associated with sickle cell trait?
- What ethical questions must be addressed for people who have sickle cell trait?
- What public perceptions and myths remain about people who have SCD, and how do we rid the disease of its stigma?
- How does SCD affect individuals and social institutions, such as health care, employment, and education?
- What personal or parental responsibilities does carrier status involve?

“We need to know our own family histories. I never knew an aunt and uncle had sickle cell disease. We need the public and the doctors to be better educated for the next generation.”

—Michael McCoy, father of two children who have SCD

The public is just beginning to focus on these issues. A June 2009 article in the *American Journal of Public Health* addressed clinical and ethical issues in managing carrier status. That same month, the National Collegiate Athletic Association won a court case related to its recommendation of testing college athletes for SCD to prevent related injuries or deaths during athletic activities.

Racial misperceptions present another challenge to SCD awareness. Although SCD affects people from a wide variety of ethnic and geographical areas, the myth persists that the disease only affects African Americans. Additionally, within the African American community, a need exists to increase the visibility and political viability of SCD. This effort should not perpetuate the racial myth or allow “high-achieving individuals” to undermine public perceptions about the severity of the disease.

The National Heart, Lung, and Blood Institute's (NHLBI's) campaign must increase national awareness of SCD without undermining the love, caring, respect, and appreciation for those who live with the disease. It is critical that the NHLBI review and learn from past efforts, address known challenges, and rely on the actual experiences of people living with SCD to guide program development and implementation.

Talk Show: Viewpoints In Sickle Cell Disease

Moderator: Paul Berry, Paul L. Berry & Associates

Panelists:

- Michael McCoy, father and care provider for two children who have sickle cell disease (SCD)
- Tiffany McCoy, SCD patient
- J. Hoxi Jones, patient and consumer advocate for the SCD community
- Stephanie Davis, M.D., primary care physician and assistant professor, Department of Family and Community Medicine, University of Maryland School of Medicine
- Kathryn Hassell, M.D., hematologist and director of the Colorado Sickle Cell Treatment and Research Center
- Joseph Wright, M.D., M.P.H., pediatric emergency medicine physician and senior vice president, Child Health Advocacy, The Child Health Advocacy Institute, Children's National Medical Center

“It’s very important for people like me to have a role in educating and empowering people about sickle cell disease.”

—J. Hoxi Jones, SCD patient and advocate

During this session, moderator Paul L. Berry asked panelists a range of questions about medical, social, and educational issues related to SCD. Panelists provided their perspective on living and/or working with people who have SCD. Audience questions and comments were invited through the session.

Michael McCoy is the father of panelist and SCD patient Tiffany McCoy. He has two other children, one of whom has SCD that is more severe than Tiffany’s. He spoke of his joy and pride in seeing Tiffany grow into an accomplished adult, college graduate, and mother, despite the challenges of living with SCD. Mr. McCoy also shared the profound effect the disease has had on his entire family, including the shock of hearing that a child might not live to age 16, the pain a parent endures watching a child suffer, holidays and precious family time spent in hospitals, and the difficulty of ensuring appropriate time and attention to his healthy child.

Mr. McCoy expressed appreciation for the quality of care his children have received at both the National Institutes of Health and The Johns Hopkins Hospital; he gave special praise to a nurse who had provided continuing care, attention, and support over the years. However, Mr. McCoy also noted the lack of knowledge about SCD that his family has encountered in other medical settings. He described the difficulty of finding the information and resources needed to understand and manage the disease.

Tiffany McCoy and J. Hoxi Jones both discussed their ability to lead busy, productive lives, despite the obstacles that SCD presents. Ms. McCoy noted that SCD does not define her, and it is inappropriate to consider people who have SCD as victims. Both Ms. McCoy and Ms. Jones discussed the need for better access to information and support. They explained that although a vast amount of information is available, it is fragmented and difficult to find. Ms. Jones, an active health advocate, expressed hope that the National Heart, Lung, and Blood Institute (NHLBI) would target outreach efforts to the general public; one educated person can reach out to inform others. She further stressed the need for a culturally competent health care environment. Both Ms. McCoy and Ms. Jones applauded the NHLBI for undertaking this effort and for involving the workshop participants, who were “really in the SCD trenches.”

The three physician panelists—Stephanie Davis, Kathryn Hassell, and Joseph Wright—strongly supported the idea of a widespread national education effort. An increasing number of people know about SCD, and screening and genetic counseling are available in many areas. However, a lack of understanding about the disease and its complications remains, even among some health care providers.

“There are not enough physicians with sickle cell training to care for all the adults with the disease.”

—Kathryn Hassell, M.D.

Panelists emphasized a number of important issues related to health care providers, including the following:

- Families affected by SCD need caring, knowledgeable providers whom they can easily contact.
- It is essential for providers to treat the whole person, not just the disease.
- Providers need education to ensure that they fully understand SCD complications and don't just treat symptoms. Currently, patients may be assessed incorrectly because of an erroneous assumption that an unrelated medical issue is associated with the patient's SCD status.
- As children grow into adulthood, providers also must address psychosocial issues.

Drs. Davis, Hassell, and Wright expressed hope that the NHLBI will generate excitement in the field and attract new researchers to achieve a better understanding of SCD and related therapies. The most effective health care providers for SCD patients are those who take a comprehensive

approach to care and are educated about the most effective therapies.

Campaign 101: Keys to Success

Moderator: Paul Berry, Paul L. Berry & Associates

Panelists:

- Amy Pianalto, National Heart, Lung, and Blood Institute (NHLBI)
- Sue Shero, R.N., M.S., NHLBI
- Ann Taubenheim, Ph.D., M.S.N., NHLBI
- Janice Bowie, Ph.D., M.P.H., The Johns Hopkins Bloomberg School of Public Health

During this session, panel members described science-based NHLBI awareness and education campaigns, reviewed the process for developing and implementing them, and offered lessons learned that could be applied to a sickle cell disease (SCD) awareness and education campaign.

Ms. Pianalto presented an overview of COPD Learn More Breathe Better,[®] an awareness and education campaign sponsored by the NHLBI. This campaign aims to raise awareness among the approximately 12 million Americans who have chronic obstructive pulmonary disease (COPD), as well as the additional 12 million Americans who may have the disease but do not realize it. Many people who have COPD are unaware of it because they do not recognize the symptoms. The campaign encourages the target audience to get diagnostic testing and treatment for COPD. Further, campaign messages emphasize to health care providers that COPD can be easily recognized and diagnosed, and it should be treated aggressively. COPD Learn More Breathe Better[®] focuses on men and women older than 45, especially those who smoke or used to smoke. The campaign team produced educational materials

[®] COPD Learn More Breathe Better is a registered trademark of the U.S. Department of Health and Human Services (HHS).

for the public, including public service announcements (PSAs) for radio and print, fact sheets, a Web site, and a video. The team also developed a speaker's guide, which contains a peer-to-peer presentation for health care providers and talking points for speakers making public presentations. In addition, the team developed a pocket-sized reference card for health care providers. The campaign relies on a strong coalition of voluntary, State, and local community organizations to help disseminate messages and materials.

“Even though people with sickle cell disease often present at the emergency room in crisis, emergency room doctors generally don’t understand the disease because they see it so rarely.”

—Joseph Wright, M.D., M.P.H.

Ms. Shero described Stay in Circulation: Take Steps to Learn About P.A.D., a national campaign to increase public and health care provider awareness of peripheral arterial disease (P.A.D.) and its association with other cardiovascular diseases. The campaign targets adults older than 50 who are at risk for P.A.D., particularly African Americans. For this campaign, the NHLBI partnered with the P.A.D. Coalition, other national and community-based organizations, and nonprofits and corporations. A community action kit was developed to help partners support national activities. The campaign uses PSAs, a video, educational materials, a Web site, and mass media to deliver messages to the public.

Dr. Taubenheim spoke about *The Heart Truth*,[®] a national campaign to raise awareness among women about heart disease. The campaign targets women between the ages of 40 and 60. The campaign's objectives are to raise awareness that heart disease is the #1 killer of women, and to urge women to talk with their health care providers about their personal risk for heart disease and take action to lower that risk.

A traditional social marketing approach, including an extensive formative research phase, was used to plan, implement, and evaluate the campaign. Input from partner organizations and focus groups conducted with women across the country also informed the campaign's development. The NHLBI secured former First Lady Laura Bush as the campaign's national spokesperson. The Red Dress[®]—created by the NHLBI as the national symbol for women and heart disease awareness—is the creative centerpiece of the campaign. Key campaign implementation strategies include a road show, which offers heart disease risk factor screenings; community programming; partnership development; an outreach program for women of color; dissemination of educational materials; and a series of keynote events, such as National Wear Red Day[®] and The Red Dress[®] Collection Fashion Show.

Dr. Bowie offered an overview of the role of formative research, a critical first step that guides program development. The importance of formative research cannot be overstated—without this step, program failure is likely. Formative research helps planners determine the most appropriate target audiences; which approaches will best reach the intended audiences; what messages, settings, and delivery mechanisms will resonate with the target audiences; and how to best determine campaign effectiveness. Formative research may include input from experts, such as those attending

[®] *The Heart Truth* and The Red Dress are registered trademarks of HHS.

[®] National Wear Red Day is a registered trademark of HHS and the American Heart Association.

the SCD workshop; literature reviews and media scans; interviews and focus groups with target audiences; input from potential partner organizations that can reach the intended audiences; and testing of themes, messages, and materials with intended audiences prior to finalization.

The potential beneficiaries of any campaign must be involved in the planning process. For the SCD awareness campaign, it will be essential to reach out to diverse groups of stakeholders, including members of African American and other minority groups, SCD patients, health care providers, employers, and others. Formative research provides the mechanism for hearing the input of target audiences, determining awareness level, and understanding audience beliefs and feelings about SCD. Finally, formative research adds credibility and value to the effort; it reflects the needs and values of the target audiences and reassures planners that their work addresses those needs.

The NHLBI campaigns all have common elements that make them successful, including the following:

- **Formative research.** This research can yield significant and sometimes surprising information. For example, for the COPD campaign, planners wanted to tell the target audience to stop smoking. Research showed that the audience would not listen or respond to this message. Therefore, planners amended the message to one the audience would accept—focusing on risk factors for COPD and steps to take for early diagnosis. Research for the P.A.D. campaign also showed that people were unfamiliar with P.A.D. As a result, the team developed campaign messages, focused the messages on the disease and outcomes people could understand (e.g., heart attack and stroke), targeted those at greatest risk (African Americans and people older than 50), and offered action steps.
- **Partners.** The NHLBI always relies on a strong network of partners to help extend the reach of its campaigns and expand resources. Partners also are essential for ensuring sustainability after initial program implementation. Moreover, campaign partners can be effective advocates for the issue and funding needs.
- **Resources.** Regardless of the funding level, resources are never sufficient. National campaigns are expensive, and determining funding priorities can be difficult. Usually campaign implementation strategies must be approached incrementally. However, corporations sometimes can be engaged to support a campaign through paid advertising, sponsorship of key activities, or in-kind contributions. For example, in 2009, in partnership with *The Heart Truth*[®] campaign, Diet Coke spent more than \$60 million in promoting campaign messages on television and placing the signature Red Dress logo on 6.1 billion packages, bottles, and cans of Diet Coke.
- **Strategies.** New technology is changing traditional methods for communicating with and reaching audiences. Television and print PSAs are not as useful as they once were because of lack of control over their placement and timing. Today, campaign planners must incorporate vastly popular social networking and Web-based approaches into their implementation strategies. Well-known spokespersons, such as Laura Bush, add prestige to and recognition of a health issue or disease; other examples include Michael J. Fox for Parkinson's disease; Magic Johnson for HIV/AIDS; and Jerry Lewis for muscular dystrophy.
- **Evaluation.** Each successful NHLBI campaign budgeted for process and outcome evaluations. Program evaluation is a critical step in the health communications process. For example, the NHLBI used a measurable objective—awareness of heart disease—to

assess the effectiveness of *The Heart Truth*[®] effort. Before the campaign began, only 34 percent of women knew that heart disease was the #1 killer of American women. In 2009, that number had grown to 68 percent.

In summary, successful campaigns are built on well-established, evidence-based communication principles. Effective planning involves setting priorities; doing formative research; creating unified messages that resonate with intended audiences; understanding the needs of target audiences by asking, listening, and responding; identifying key partners; creatively combining both traditional methods and emerging health communication strategies to reach target audiences; and planning for outcome assessment.

Overview of the Results of an Environmental Scan on Existing Sickle Cell Disease Campaigns and Major Education Efforts

Edward Donnell Ivy, M.D., M.P.H., Medical Officer, Enhanced Dissemination and Utilization Branch, Division for the Application of Research Discoveries, National Heart, Lung, and Blood Institute

As part of its preparation for the sickle cell disease (SCD) workshop and campaign, the National Heart, Lung and Blood Institute (NHLBI) asked the American Institutes for Research[®] to conduct an environmental scan of campaigns and campaign evaluations related to SCD within the past 5 years. The process included a literature review and a Web search.

Thirty campaigns within the United States were identified as occurring between 2004 and 2009, along with five publications relevant to campaign evaluation. Among the campaigns, 10 were national and 20 were smaller scale, regional campaigns. Exhibit 4 outlines the number of campaigns that used various channels, target audiences, and key messages, which were identified in the environmental scan.

Most campaigns were intended to raise awareness of SCD or provide education about SCD to patients and families. A smaller number of campaigns encouraged action through blood donation or fundraising. The number of campaigns may indicate a low level of knowledge about SCD in the general public and among the specific racial and ethnic groups at increased risk for the disease.

In total, 17 campaigns targeted the general public, 8 focused on patients who have SCD or families affected by SCD, 9 focused specifically on the African American community, and 3 focused on the medical community, such as physicians. Campaigns focused on raising awareness generally targeted the overall population, whereas campaigns focused on patient education more often targeted populations at highest risk for SCD. Some campaigns focused on a specific event, such as an annual walkathon or SCD awareness day, while others continued over multiple years. For example, the annual National Stomp Out Sickle Cell Walk consisted of 13 regional walks held on the same day or during Sickle Cell Awareness Month (September).

The campaigns have used a number of strategies to raise awareness and educate about SCD. These strategies include:

- Health fairs (the most frequently used strategy), blood drives, organized walks or observances focused on raising awareness, and other community events.
- Music and arts events, including a jazz event fundraiser, a CD-release party for inspirational music composed specifically to uplift SCD patients, and a display of work from contemporary artists intended to promote SCD awareness.
- Outreach in a variety of settings, such as grocery stores, YMCAs, schools, community organizations, and churches.
- Informational campaigns.
- Spokespersons delivering messages about SCD to various communities.

Pharmaceutical manufacturer Novartis and the Sickle Cell Disease Association of America sponsored campaigns featuring well-known spokespersons who did not have the disease but were willing to help raise awareness through community outreach and public speaking. However, the rationale for using celebrity spokespersons was not always clear.

The campaigns used multiple strategies and methods to disseminate information. However, few provided guidance on treatment or health maintenance options. These campaigns also did not appear to provide information to medical and health professionals who treat SCD patients.

In summary, the environmental scan found only a limited number of campaigns. The focus of these campaigns was primarily on general awareness, rather than treatment options, management, or prevention of SCD complications. In addition, campaign results often lacked information on the success of the events (e.g., attendee turnout or distribution volume of any awareness materials). As the NHLBI goes forward with the SCD awareness and education campaign, these findings underscore the importance of defining goals, determining benchmarks and measurable targets, identifying audience(s) and appropriate partners, and developing long-term followup measures.

Exhibit 4. Number of Campaigns Identified in the Environmental Scan

	Channels		Target Audiences		Key Messages	
Regional Total	Radio	1	General public	15	Raise awareness	13
	News	0	Patients	4	Donate blood	2
	TV	1	African Americans	5	Raise funds	5
	Public events	10	Multiple of other ethnicities	4	Patient education	9
	Spokespersons	0	Medical community	2	Other	2
	Organized walks and observances	8	Other groups	2		
	Written materials	2				
	Music and arts	5				
	Other	3				
National Total	Radio	1	General public	2	Raise awareness	6
	News	1	Patients	4	Donate blood	0
	TV	0	African Americans	4	Raise funds	1
	Public events	3	Multiple of other ethnicities	1	Patient education	6
	Spokespersons	5	Medical community	1	Other	0
	Organized walks and observances	3	Other groups	1		
	Written materials	1				
	Music and arts	1				
	Other	0				
Grand Total	Radio	2	General public	17	Raise awareness	19
	News	1	Patients	8	Donate blood	2
	TV	1	African Americans	9	Raise funds	6
	Public events	13	Multiple of other ethnicities	5	Patient education	15
	Spokespersons	5	Medical community	3	Other	2
	Organized walks and observances	11	Other groups	3		
	Written materials	3				
	Music and arts	6				
	Other	3				

September 3, 2009

Welcome, Day 2

W. Keith Hoots, M.D., Director, Division of Blood Diseases and Resources, National Heart, Lung, and Blood Institute

The National Heart, Lung, and Blood Institute (NHLBI) is committed to advancing sickle cell disease (SCD) awareness and education efforts and programming. The Institute recognizes that a broad need exists for SCD research—basic, translational, clinical, and comparative—to examine and compare specific therapies for efficacy and cost. To meet this need, the NHLBI works with Federal partners to advance knowledge about surveillance and research priorities. Additionally, the NHLBI aims to invoke support, engender research, and foster career-long training of the next generation of hematologists and other specialists in blood diseases. The NHLBI research agenda is global, as members of the SCD population are truly citizens of the world.

The NHLBI's Division of Blood Diseases and Resources (DBDR) supports research on the causes, prevention, and treatment of nonmalignant blood diseases, including anemias, SCD, and thalassemias; premalignant processes such as myelodysplasia and myeloproliferative disorders; hemophilia and other abnormalities of hemostasis and thrombosis; and immune dysfunction. The DBDR funds research that ranges in scope from basic biology to medical management of blood diseases. Research and training programs on SCD are part of the Blood Diseases Branch, led by acting branch chief Dr. Harvey Luksenburg.

Under the guidance of the Blood Diseases Branch, research on SCD covers a range of areas, from examining etiology and pathophysiology to improving disease treatment and management. Areas of emphasis include genomic evaluation of hemoglobinopathies, development of animal models of disease, regulation of hemoglobin synthesis, iron chelation, development of drugs to increase fetal hemoglobin production, hematopoietic transplantation, and gene therapy.

The NHLBI's SCD research includes basic through phase III clinical trials. Ongoing research includes a study on hydroxyurea for the treatment of SCD in children (SWITCH). Upcoming trials include Transcranial Doppler Velocities With Transfusion Changing to Hydroxyurea (TWiTCH), a phase III clinical trial of a novel therapy to reduce the risk of stroke and prevent iron overload in children who have sickle cell anemia. The Institute currently is working on new strategies for launching SCD clinical trials. SCD clinical trials require commitments from the community for studying this rare but important disease.

Additionally, the NHLBI DBDR and the Centers for Disease Control and Prevention are working together to improve the ability to identify and register—with permission—every person in the United States who has a hemoglobinopathy, to determine where to best focus research and education efforts. The NHLBI also is developing guidelines for medical professionals treating people who have SCD, which, in conjunction with a national hemoglobinopathy registry, will lead to better quality of life, better care, and easier access to care for people who have SCD nationwide.

Public Health Outreach and Sickle Cell Disease Programming at the Centers for Disease Control and Prevention and the Health Resources and Services Administration

Hani Atrash, M.D., M.P.H., Director, Division of Blood Disorders, Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention's (CDC's) mission is to oversee the health of the Nation's population. Public health plays a major role in wellness and surveillance research, which is accomplished in collaboration with State and local health departments across the country.

As represented in Healthy People 2010 (a framework for national health objectives developed

by the U.S. Department of Health and Human Services), some criteria for weighing the importance of a health issue include prevalence, severity, mortality, community concern, lost productivity, premature mortality, medical cost to treat, feasibility to prevent, and disparities. These issues are all relevant to sickle cell disease (SCD). Journal publications have shown a considerable increase in attention to SCD in recent years, particularly in covering morbidity, mortality, and costs associated with the disease.

Until recently, the approach to SCD has been isolated and sporadic. However, national and international efforts have emerged to coordinate activities and establish comprehensive programs, including a number of international conferences addressing SCD. In Europe, interest in SCD has begun to overtake other familiar genetic diseases, such as hemophilia and cystic fibrosis. Internationally, coordinated efforts are under way to design and implement equitable and systematized programs covering education and awareness, surveillance, treatment, counseling, and screening. These efforts also aim to support appropriate provider training and research.

In the United States, new efforts also are under way or have occurred, including a Health Resources and Services Administration (HRSA) grant to States to improve SCD screening programs for newborns, the National Heart, Lung, and Blood Institute's (NHLBI's) 2006 workshop to develop health objectives for people who have SCD, and an American Society of Pediatric Hematology/Oncology 1997 summit on SCD to support a vision of an "adequately funded, coordinated, comprehensive, and integrated national model for care of persons with SCD."⁹

The CDC supports an approach to SCD that is comprehensive, organized, coordinated, institutionalized, and sustainable. Many other Federal

In the area of sickle cell disease, the CDC's goals are to:

- Speak with a unified voice representing all constituencies.
- Optimize access to care from knowledgeable health care providers and create a medical home for everyone who has the disease.
- Utilize population-based surveillance to measure outcomes.
- Develop overall approaches to basic, translational, clinical, and health services research.
- Ensure the community's role in advocacy, education, service, and fundraising.

Agencies are working with the CDC on blood disorder services, including the National Institutes of Health (NIH), the HRSA, the Agency for Healthcare Research and Quality, and the U.S. Food and Drug Administration. Over the years, the CDC's activities related to SCD have included the establishment (with NIH support) of a hemoglobinopathy laboratory in 1972, 19 screening and education clinics, and a national reference laboratory for SCD. The CDC also has developed numerous publications using national and State data from the National Hemoglobinopathy Standardization Laboratory.

Today, the CDC's activities include a number of internally coordinated efforts related to epidemiology, surveillance, and health research services; behavioral sciences and health education; awareness (both internally and publicly through the "Morbidity and Mortality Weekly Report," journal publications, and the CDC.gov Web site); and information sharing and dissemination (through journal publications and conference presentations). The CDC is working to strengthen its partnership activities with Federal Agencies, State health departments, and community-based

⁹ American Society of Pediatric Hematology/Oncology. (2007). Sickle cell disease summit: From clinical and research disparity to action. *Proceedings of the American Society of Pediatric Hematology/Oncology*. Retrieved from http://www.aspho.org/pdf/Summit_full_proceedings.pdf

organizations. In addition, the CDC is establishing a multifaceted SCD program.

The NHLBI is funding an interagency agreement with the CDC to conduct the registry and surveillance system for hemoglobinopathies (RuSH). RuSH is a pilot program to develop an infrastructure for a hemoglobinopathies registry and surveillance system and to improve information-sharing capabilities among the States. The CDC will issue cooperative agreements to selected States that will coordinate the collection and sharing of information about residents who have SCD and thalassemia. The agreements will be finalized very early in 2010.

**R. Lorraine Brown, R.N., Public Health Analyst,
Health Resources and Services Administration**

The HRSA is the Nation's access agency. Its role is to improve health and save lives by ensuring that the right services are available in the right places at the right time. The HRSA supports the National Hemophilia Program, the Thalassemia Comprehensive Care projects, and the Sickle Cell Disease and Newborn Screening Program as models of comprehensive care for delivery of genetic services, testing, counseling, education, and coordinated systems of services across the lifespan. The SCD program is part of the Maternal and Child Health Bureau's Division of Services for Children With Special Health Needs. The program focuses on family and professional partnerships; the concept of coordinated, ongoing, comprehensive care within a medical home; insurance; early and continuous screening; integrated community-based services; and transition to adult life.

The HRSA's Newborn Screening Program was started in 2002 with 15 States to enhance followup of State screening programs. The program is in the fourth round of funding grantees, with six original grantees in place throughout the 7 years of funding. The HRSA currently has 17 grantees focusing on newborn screening followup for SCD and sickle cell trait and is addressing outreach to emerging populations.

The HRSA-funded pilot efforts have identified several problem areas: lack of parental and provider education, little or no followup after screening, and minimal documentation about followup. The National Coordinating and Evaluation Center for the Sickle Cell Disease and Newborn Screening Program, based in North Carolina and funded by the Sickle Cell Disease Association of America, is supporting the implementation of community-based projects for SCD and newborn screening. This effort is designed to educate parents and families; strengthen partnerships; improve followup activities for newborns who have SCD or sickle cell trait; develop educational materials in English and Spanish for the entire SCD community; and address the needs of emerging populations.

The HRSA also funds SCD treatment demonstration programs to increase the capacity and capability of eligible ambulatory health care delivery entities that coordinate service delivery, genetic counseling, and testing. These demonstration programs also train health care providers in the care of people who have SCD or sickle cell trait. Four networks are in their final year of funding in urban, suburban, rural, and university settings. The programs' accomplishments to date include:

- Participating in a learning collaborative.
- Completing the Medical Home Index (MHI) tool for networks, and development of priorities based on the MHI assessment.
- Enrolling 100–150 people in the program network, representing a spectrum of ages.
- Linking SCD patients to a medical home.
- Piloting a care-card identification system.
- Drafting an algorithm flowchart for pediatric and adult care.
- Establishing standards of care for adults.
- Developing and testing two formats of a comprehensive care coordination tool.

New legislation, the Newborn Screening Saves Lives Act of 2007, was established under Title XXVI of the Children's Health Act of 2000, Screening for Heritable Disorders. This law reauthorized and expanded the role of the Advisory Committee on Heritable Disorders in Newborns and Children, and also expanded newborn screening through a grants program. The HRSA currently is in the process of hiring staff, some of whom will conduct SCD education and outreach. The program will include an

interagency coordinating committee, research on newborn screening technologies, management of the disease detected through screening, an Internet-based clearinghouse of information for heritable disorders managed by the HRSA, and laboratory quality and surveillance managed by the CDC. The HRSA also funds the National Newborn Screening and Genetics Resource Center and a number of additional education and support resources for families affected by SCD.

Recommendations for a Sickle Cell Disease Awareness and Education Campaign

During the 2-day workshop, participants representing many professional and advocacy organizations, patients, and family members worked in small group sessions. The charge to the small workgroups was to consider and report to the National Heart, Lung, and Blood Institute (NHLBI) their priority recommendations for developing a national sickle cell disease (SCD) awareness and education campaign. Participants enthusiastically embraced their charge, discussing campaign target audiences, messages, implementation strategies, and potential partners. Using a consensus-building process, the workshop moderator guided the participants in narrowing their target audience recommendations to three broad groups:

- Health care providers
- Patients who have SCD and their families
- The general public

Workshop participants developed broad overall recommendations for a national SCD campaign. These included:

- Educate primary care providers about SCD management for patients of all ages.

- Raise awareness among targeted segments of the general public about SCD and sickle cell trait and its implications.
- Encourage people who have SCD or sickle cell trait to become empowered about their health and seek appropriate medical care.

Participants envisioned a multiyear, multipronged effort with a scope that is national, regional, and community based. They also recommended working with well-known national entertainment, professional, and sports-related partner organizations to help educate the public, influence the health behaviors of people affected by SCD, and encourage health care providers to use the NHLBI's upcoming SCD guidelines.

Discussions were productive and detailed, producing a large number of recommendations. In the small groups, participants identified many subsets within the recommended broad target audiences and generated a variety of ideas for campaign messages and implementation strategies. Participants strongly advocated for their recommendations, particularly the critical need to reach all three proposed target groups. However, participants did not reach a consensus when asked to prioritize the target audiences or the potential campaign messages and partners.

The workshop participants' overall recommendations were as follows:

- Target audiences. Broad target audience categories and specific subsets included:
 - Health care providers and allied health care professionals, such as primary care physicians, emergency physicians, pulmonary specialists, emergency room and emergency services personnel, nurses, nurse practitioners, physician assistants, behavioral practitioners, medical students, social workers, and others who regularly interact with people who have SCD.

- The general public, divided into subsets that include different age groups, ethnicities, and races, including those who have sickle cell trait.
- Affected populations—people who have SCD and their families.
- Campaign messages. For all audiences, participants suggested messages that dispel the myth that SCD only affects African Americans and the social stigma SCD may carry. Participants recommended research-based messages that are tailored to each audience and subgroup. Messages directed at health care providers should urge them to adopt new standards of medical care for SCD management over the lifespan. Messages directed at the public should urge awareness of SCD and sickle cell trait. Messages for affected populations should encourage awareness about seeking improved medical care and quality of life.
- Implementation strategies. Participants recommended a range of health communication and education strategies. For health care providers, strategies included developing and disseminating medical standards of care for SCD, educational toolkits, various print items (e.g., reference cards), and electronic tools (e.g., DVDs and podcasts). Participants also recommended that health care providers take advantage of continuing education programming on SCD. For the general public and patients, participants recommended procuring a nationally recognized spokesperson to deliver campaign messages. They also recommended using print, electronic, and Web-based media, as well as information/presentations appropriate for Black Family Reunions and other suitable national and local events.
- Partnerships. Partnerships will be key to successful SCD outreach efforts. For health care providers, potential partners include professional organizations and societies, schools of medicine and public health, and accreditation and licensing organizations.

For the general public and affected populations, potential partners include Federal, State, and local government agencies; volunteer organizations; community-based, sports, and entertainment organizations; and the media. Workshop participants emphasized the importance of establishing outcome measurements to determine program effectiveness.

In conclusion, workshop participants provided the NHLBI with a general framework for developing a SCD awareness and education campaign. This framework represents their various perspectives, backgrounds, and experiences with SCD. As the NHLBI begins to develop and implement the campaign, the participants' recommendations will serve as a starting point for identifying and addressing the many unmet needs of the SCD community. For more detailed information about the participants' recommendations, see exhibit 5.

Moving Forward

Next Steps: Where Do We Go From Here?

W. Keith Hoots, M.D., Director, Division of Blood Diseases and Resources, National Heart, Lung, and Blood Institute

The National Heart, Lung, and Blood Institute (NHLBI) has successfully developed and implemented other national awareness and education campaigns, and will draw on its breadth of experience in developing new education and awareness strategies for sickle cell disease (SCD).

As a critical first step in strategy development, this workshop has yielded many valuable perspectives and recommendations from the people most affected by SCD—people who have SCD and their families, other caregivers, and health care providers.

A written report summarizing the workshop proceedings and the recommendations generated will be prepared and distributed to workshop participants and NHLBI leadership. NHLBI staff from the Office of the Director, Division of Blood

Diseases and Resources (DBDR), Division for the Application of Research Discoveries (DARD), and Office of Communications will carefully review all of the workshop recommendations.

The NHLBI Office of Communications will take the lead in developing the Institute's SCD national campaign, and the DBDR will support the campaign development efforts. The campaign development team will work closely with the DARD, whose staff are currently developing the NHLBI's SCD guidelines.

The NHLBI will solicit proposals from experienced organizations and award a contract for development and launch of the SCD awareness and education campaign. The contractor will work closely with NHLBI staff and use the workshop report as a key resource for developing a strategic campaign plan. The new SCD campaign also will encompass the Healthy People 2020 objectives, including the elimination of health disparities.

The NHLBI expects to undertake a number of SCD-related activities in addition to support of campaign efforts, including the RuSH program and several new clinical trials. A major challenge is to train nonhematologists in the patient care necessary for clinical trials. The Institute will address such challenges and work on strategies to improve participation and retention in these trials. The Institute also will work to improve the funding of basic science grants pertaining to SCD. Future research possibilities include both embryonic hematopoietic stem cell and induced pluripotent stem cell studies for possible use in transplantation research for treating hemoglobinopathies.

The NHLBI expects to assemble a group of Federal partners who will make a concerted effort to develop parallel SCD activities and programming to coincide with the campaign launch. The NHLBI will build on and extend its existing partnerships for this effort and commits to keeping the SCD community informed about progress.

Exhibit 5. Workgroup Recommendations			
Target Audiences	Messages	Implementation Strategies	Potential Partners
<p>Health Care Providers and Allied Health Care Professionals</p> <ul style="list-style-type: none"> ■ Primary care physicians ■ Emergency physicians ■ Pulmonary specialists ■ Emergency room and emergency services personnel ■ Nurses, nurse practitioners, and physician assistants ■ Behavioral practitioners, medical students, and social workers ■ Others who regularly interact with people who have SCD 	<ul style="list-style-type: none"> ■ SCD has many faces, not all of which are African American. The disease also affects Hispanics, Caucasians, and other populations, including those from South and Central America, Caribbean islands, Mediterranean countries, and Saudi Arabia. ■ People who have SCD can now live long and productive lives. ■ The NHLBI is developing new SCD guidelines for the care of people who have SCD across their lifespan. ■ SCD patients who are in transition from childhood through adolescence into adulthood have crosscutting medical and psychosocial needs. ■ Medical home concepts can be effective and efficient in providing specialty care in one setting for SCD patients. ■ Treating acute SCD-related incidents to prevent complications is different from maintaining patient health over a lifetime. ■ SCD patients presenting at emergency settings are not drug seekers; they need appropriate medical attention, as addressed in the NHLBI's forthcoming SCD guidelines. 	<ul style="list-style-type: none"> ■ Develop and disseminate new NHLBI SCD guidelines. ■ Develop SCD education materials for medical schools, residency programs, and schools of public health. ■ Develop and disseminate comprehensive, multicomponent, professional education toolkits. ■ Create electronic fact sheets, physician reference cards, and other appropriate materials. ■ Create opportunities for continuing medical education credit and units, board certification, and accreditation for medical and allied health care professionals. ■ Build a strong partnership network to help inform the campaign and disseminate messages and materials. ■ Enlist partner support for needed policy changes. 	<ul style="list-style-type: none"> ■ Appropriate Federal Government and military organizations ■ Schools of medicine and public health ■ State and local health departments ■ Professional associations and societies ■ Accreditation and licensing organizations ■ Local hospitals and medical centers ■ African American and Latino health organizations ■ Blood suppliers and blood banks ■ Medical suppliers ■ Foundations

Exhibit 5. Workgroup Recommendations (continued)

Target Audiences	Messages	Implementation Strategies	Potential Partners
<p>General Public</p> <ul style="list-style-type: none"> ■ The general population, including those who have sickle cell trait ■ Minority populations ■ Emerging populations ■ Different groups of all ages 	<ul style="list-style-type: none"> ■ The public should be informed about SCD. ■ It is important for people to know their carrier status (i.e., whether they have sickle cell trait) and realize its implications. ■ SCD has many faces, not all of which are African American. ■ People who have SCD can lead long and productive lives. ■ The public should take this action step to learn more (action step to be decided). ■ People should feel empowered to take charge of their own health. 	<ul style="list-style-type: none"> ■ Enlist a nationally recognized spokesperson to deliver campaign messages about SCD. ■ Consider issuing a new postage stamp to promote SCD awareness. ■ Enlist partner organizations (corporations, businesses, local governments, community-based organizations) to promote awareness and place educational information on range of products (billboards, buses, shopping carts, movie screen advertisements, etc.) ■ Use print, electronic, and Web-based media to help disseminate messages to targeted audiences. ■ Make SCD information available at Black Family Reunions, concerts, local businesses, and other cultural events. ■ Enlist minority-oriented partner organizations to assist in awareness and education efforts. ■ Hold an annual national SCD awareness day and promote related activities at local health fairs, church events, and other community gatherings 	<ul style="list-style-type: none"> ■ Appropriate Federal Government organizations ■ Appropriate local government organizations, including health departments, schools, libraries, etc. ■ National volunteer and nonprofit organizations focusing on SCD ■ National organizations, especially those that have minority members or those seeking to increase their minority membership ■ Historically Black colleges and universities ■ Community-based groups, including health-based, civic, social, nonprofit, faith-based, education, and business organizations (for example, barber shops, pharmacies, grocery stores, insurance companies, child care, and other health-related business organizations) ■ National sports organizations ■ Corporations, including those with a minority focus ■ Foundations ■ The Ad Council ■ Media (print, electronic, Web-based, social marketing, etc.)

Exhibit 5. Workgroup Recommendations (continued)

Target Audiences	Messages	Implementation Strategies	Potential Partners
<p>Affected Populations</p> <ul style="list-style-type: none"> ■ People who have SCD ■ Families of people who have SCD ■ People who have sickle cell trait ■ Emerging populations 	<ul style="list-style-type: none"> ■ People should feel empowered to take charge of their own health. ■ It is important for people who have SCD to work with health care providers who understand the disease. ■ People who are affected by SCD should ignore myths about the disease. ■ People who have SCD can lead long and productive lives. ■ No stigma should be attached to having SCD or sickle cell trait. ■ People who have sickle cell trait should take this action step (action step to be determined). 	<ul style="list-style-type: none"> ■ Build a strong national partnership network with ties to local, community-based, grassroots organizations with the potential to reach affected populations. ■ Create advocacy toolkits for nonprofit organizations. ■ Create mechanisms for facilitating peer-to-peer education and counseling. ■ Create educational products for print, DVD, podcast, and Web placement. ■ Provide regular updates for the SCD community on the progress of the NHLBI campaign. 	<ul style="list-style-type: none"> ■ Community-based organizations with existing or potential interest in SCD, such as civic, social, educational, faith-based, health-related groups, etc. ■ Patient groups ■ National, State, local, and other health associations and societies ■ Local medical organizations, clinics, hospitals, and physician group practices ■ Blood suppliers and blood banks ■ Local organizations working with minorities ■ Minority-owned businesses ■ National, regional, and community sports organizations ■ Media, such as Web-based social networking sites

Appendix: Workshop Agenda and Participant List





Appendix A: Workshop Agenda

National Heart, Lung, and Blood Institute Sickle Cell Disease Awareness and Education Strategy Development Workshop September 2–3, 2009

September 2, 2009

- 8:00–8:30 a.m. Registration
- 8:30–8:45 a.m. **Welcome and Introduction**
Elizabeth G. Nabel, M.D.
Director, National Heart, Lung, and Blood Institute
- 8:45–9:25 a.m. **Opening Session: A Call for Action**
Lanetta Jordan, M.D., M.P.H., M.S.P.H.
Sickle Cell Disease Association of America
- 9:25–9:35 a.m. **Setting the Stage: Why We Are Here?**
Workshop Goals and Objectives
Workshop Moderator: Lisa Ross
- 9:35–9:50 a.m. Break
- 9:50–11:20 a.m. **Talk Show: View Points in Sickle Cell Disease**
Moderator: Paul Berry
Panelists:
 - Michael McCoy, Father and Care Provider
 - Tiffany McCoy, Patient
 - Stephanie Davis, M.D., Primary Care Physician
 - Kathryn Hassell, M.D., Hematologist
 - J. Hoxi Jones, Patient
 - Joseph Wright, M.D., M.P.H., Emergency Room Physician
- 11:20–11:50 a.m. **Opportunities and Challenges for Sickle Cell Disease Awareness in the United States**
Carlton Haywood, Jr., Ph.D., M.A., Johns Hopkins University
- 11:50–12:05 p.m. Lunch

12:05–1:05 p.m.	<p>Campaign 101: Keys to Success Moderator: Paul Berry Panelists:</p> <ul style="list-style-type: none"> ■ Ann Taubenheim, Ph.D., M.S.N., NHLBI ■ Amy Pianalto, NHLBI ■ Sue Shero, R.N., M.S., NHLBI ■ Janice Bowie, Ph.D., M.P.H., Johns Hopkins Bloomberg School of Public Health
1:05–1:20 p.m.	<p>Overview of the Results of an Environmental Scan on Existing Sickle Cell Disease Campaigns and Major Education Efforts Edward Donnell Ivy, M.D., M.P.H., NHLBI</p>
1:20–1:30 p.m.	<p>Breakout Group Instructions Lisa Ross</p>
1:30–2:15 p.m.	<p>Small Group Session #1: Identify Key Target Audience(s) for the Campaign</p>
2:15–2:30 p.m.	<p>Break</p>
2:30–3:30 p.m.	<p>Small Group Reports: Session #1 Moderator: Lisa Ross</p>
3:30–3:35 p.m.	<p>Breakout Group Instructions Lisa Ross</p>
3:35–4:35 p.m.	<p>Small Group Session #2: Key Campaign Messages for the Target Audience(s)</p>
4:35–5:20 p.m.	<p>Small Group Reports: Session #2 Moderator: Lisa Ross</p>
5:20–5:30 p.m.	<p>Day One Wrap-up</p>

September 3, 2009

- 8:30–8:45 a.m. **Welcome**
W. Keith Hoots, M.D.
Director, Division of Blood Diseases and Resources, NHLBI
- 8:45–9:20 a.m. **Public Health Outreach and Sickle Cell Disease Programming at the Centers for Disease Control and Prevention and Health Resources and Services Administration**
Hani Atrash, M.D., M.P.H., Centers for Disease Control and Prevention
R. Lorraine Brown, R.N., Health Resources and Services Administration
- 9:20–9:30 a.m. Breakout Group Instructions
Lisa Ross
- 9:30–10:30 a.m. **Small Group Session #3: Recommendations for National Campaign Strategies, Community Settings, and Channels for Delivering Messages**
- 10:30–10:45 a.m. Break
- 10:45–11:45 a.m. Small Group Reports: Session #3
Moderator: Lisa Ross
- 11:45–12:30 p.m. Lunch
- 12:30–12:40 p.m. Breakout Group Instructions
Lisa Ross
- 12:40–1:40 p.m. **Small Group Session #4: Identifying Potential Partners To Work With the NHLBI in Implementing and Evaluating the Campaign**
- 1:40–2:40 p.m. Small Group Reports: Session #4
Moderator: Lisa Ross
- 2:40–3:00 p.m. **Summary and Closing: Where Do We Go From Here?**
W. Keith Hoots, M.D.
Lisa Ross
- 3:00 p.m. Adjourn

Appendix B: Workshop Participants

**National Heart, Lung, and Blood Institute
Sickle Cell Disease Awareness and Education Strategy
Development Workshop
September 2–3, 2009**

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