

# International Public Health Learning Collaborative on Hemoglobinopathies Summary Report

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## Acknowledgements

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## About Hemoglobinopathies

The body produces three types of blood cells: red (which deliver oxygen to the body), white (which provides immune system defense), and platelets (which are the source of growth factors) (1). Of these three, the red blood cells contain hemoglobin, an iron-rich protein responsible for carrying oxygen from the lungs to all parts of the body (2). *Hemoglobinopathies* are a group of inheritable disorders in which there is abnormal production or structure of the hemoglobin molecule (3). These disorders include both sickle cell disease (SCD) and thalassemia.

SCD is a hemoglobinopathy in which the body makes an abnormal form of hemoglobin, causing red blood cells to form a sickle- or crescent-shaped red blood cell instead of a disc-shaped cell. Although there are several forms of the disease, sickle cells typically are rigid and sticky and have a tendency to clump, obstructing flow in blood vessels. Blood flow restriction can cause incidents of extreme pain, also known as *crises*, as well as chronic damage to vital organs (4).

In the United States, there are about 1,800 (5)–2,000 (6) babies born with SCD annually, approximately 70,000–100,000 individuals living with SCD, and about 3 million people with sickle cell trait (affecting people of African descent for the most part) (7). SCD is most common in West and Central African countries, where as many as 40% (8) of the people have sickle cell trait and 1%–2% of all babies are born with a form of the disease (9).

Similar to sickle cell there are various types of thalassemia, each caused by missing or altered inherited genes. If the body does not make enough protein or if the protein is abnormal, red blood cells will not form correctly or deliver adequate levels of oxygen to the body (10). Alpha thalassemias most often affect people of Southeast Asian, Indian, Chinese, or Filipino origin or ancestry. Beta thalassemias most often affect people of Mediterranean (Greek, Italian, and Middle Eastern), Asian, or African origin or ancestry (11).

The severity of complications from SCD and thalassemia vary, along with quality of life and lifespan.

Treatment methods, though successful, can cause other complications, adding to the urgency of finding more reliable methodologies and, eventually, cures for people living with hemoglobinopathies.

## Learning Collaborative Goals and Objectives

The International Public Health Learning Collaborative on Hemoglobinopathies Meeting was designed to create a forum for the exchange of information on hemoglobinopathies between countries, states, organizations, institutions, and partners who are interested in learning more about the methodologies of both federal and international programs. The objectives of the 1.5-day meeting were:

- To provide participants with a basic understanding of public health surveillance and the process, tools, and partnerships needed to create successful programs.
- To discuss lessons learned through the current programs funded through RuSH (Registry and Surveillance for Hemoglobinopathies).
- To familiarize participants with available resources for establishing, expanding, or enhancing their programs.
- To foster interaction and encourage additional partnerships among the participants.

# Learning Collaborative Presentation Summaries

## *Basics of Public Health Surveillance*

### *Public Health Surveillance With Stroke Registries as an Example*

**Paula Yoon, ScD, MPH, National Center for Chronic Disease Prevention and Health Promotion,  
Centers for Disease Control and Prevention**

Public health surveillance traditionally is defined as the ongoing systematic collection, analysis, and interpretation of health data, essential to the planning, implementation, and evaluation of public health practice, closely integrated with the dissemination of these data to those who need to know and linked to prevention and control (12). There are two key principles for public health surveillance: 1) intent—the activity is predicated on a defined public health question or problem with the purpose of protecting or promoting population health and 2) implementation — the application and use of the data are systematic and include planning and system design, data collection, analysis, interpretation, dissemination, and application to public health programs and practices.

The difference between surveillance and research is the purpose or intention of the information collected. Surveillance is the process of gathering data and knowledge in order to identify, control, or improve a health problem, public health program, or service. Research is systematic investigation with the purpose of generating generalizable knowledge.

Surveillance systems can take many forms. There are instances in which data can be collected in a single system to address health concerns. The CDC National Electronic Disease Surveillance System was established to facilitate accurate, complete, and timely reporting of infectious diseases from state and local health departments (13). Public health surveillance for noninfectious diseases, on the other hand, often is built on a framework of many indicators from many different data sources.

Sentinel surveillance is another surveillance methodology that can be used to monitor health events and can include varied data sources (14). Sentinel surveillance is of particular value when national surveillance systems are not available, large surveys would be too costly, or disease prevalence is high, and it would be impractical to collect data on every case. The main purpose of sentinel surveillance is to obtain timely information on a preventable disease or untimely death whose occurrence serves as an indicator that the quality of preventive or therapeutic care might need to be improved.

For any surveillance system, measurement standards are critical. Case definitions must be clear and, for some systems, diagnostic data might be required to validate events. Standardization of the data collection is essential for comparing population groups, geographic areas, or trends over long periods of time.

## **Resources**

Agency for Healthcare Research and Quality. Registries for Evaluating Patient Outcomes: A User's Guide: 2nd Edition (Sept 2010). Retrieved from

<http://www.effectivehealthcare.ahrq.gov/index.cfm/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=401>

Paul Coverdell National Acute Stroke Registry [http://www.cdc.gov/dhdsp/stroke\\_registry.htm](http://www.cdc.gov/dhdsp/stroke_registry.htm)

National Electronic Disease Surveillance System (NEDSS)

<http://www.cdc.gov/phin/tools/nedss/index.html>

## *National Program of Cancer Registries*

**Christie Ehemam, MSHP, PhD, National Center for Chronic Disease Prevention and Health Promotion,  
Centers for Disease Control and Prevention**

As recently as the early 1990s, there were limited data for cancer control planning. While the Surveillance, Epidemiology, and End Results (SEER) program provided data on the cancer burden for 14% of the U.S. population, these data did not provide the geographically specific information needed for the planning and evaluation of cancer control interventions at local, state, regional, and national levels. Ten states had no population-based cancer registry, and many other state registries lacked the resources and legislative support needed to gather statewide population-based data.

The 1992 Cancer Registry Amendment Act (CRAA), Public Law 102-515, authorized the Centers for Disease Control and Prevention (CDC) to establish the National Program of Cancer Registries (NPCR). The CRAA provides funds to CDC, which, in turn, funds states and territories in the enhancement or planning and implementation of such registries. In addition to providing this funding, CDC works with states to develop model legislation and regulations. Training on central registry operations is provided, and a minimum set of data items is standardized.

Legislation for the Benign Brain Tumor Cancer Registries Act passed in October 2002, amending the Public Health Service Act and authorizing the NPCR (PL 102-515) to provide for the collection of data on benign brain-related tumors for cases diagnosed on or after January 1, 2004.

A total of \$46.4 million was designated for CDC Cancer Surveillance in fiscal year 2008, and 48 programs were funded. Data on approximately 1.2 million new invasive cancer cases have been and continue to be submitted to CDC each year. There now are data on 13 million invasive cancer cases diagnosed during the period 1995–2005.



Because cancer is a reportable disease, data are collected in a highly regimented data collection system called the North American Association of Central Cancer Registries. Data items are standardized and carefully defined; structure is established and maintained for all cancer registry systems; and changes are coordinated and negotiated between CDC, the National Cancer Institute (NCI), state health departments, the Commission on Cancer, and others. CDC continues to explore ways to enhance the data through linkage with other data sets, such as the National Death Index, which provides information on vital status and cause(s) of death. Through this linkage, CDC is positioning its registries to be able to provide relative survival analysis capability.

Some challenges cancer registries encounter are incomplete or untimely reporting from physician offices, treatment facilities, and outpatient clinics; meeting the demands of increasing interest from researchers (e.g., for information on biomarkers and risk factors); and improving access to the data for research.

Within the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Cancer Surveillance Branch, the program goals include using and providing regional and national data to monitor cancer trends over time; describing cancer patterns among differing populations; guiding the planning and evaluation of cancer control programs; helping set priorities for allocation of health resources; and advancing clinical, epidemiologic, and health services research.

The NCPR and the SEER system cover the entire U.S. population, allowing analysis of the first national cancer incidence data. National coverage data promote more accurate monitoring of cancer trends over time, descriptive cancer patterns among special populations, and investigation of rare cancers. The data also are helpful in prioritizing health resources and advancing clinical, epidemiologic, and health services research.

The 2008 Annual Report to the Nation on the Status of Cancer was the first documentation of a decline in cancer incidence (15). There was a special focus on tobacco-related cancers, and state and regional differences in lung cancer trends.

Cancer registry data are a valuable resource for national, regional, and local agencies. The registry quantifies the cancer burden for particular populations by geographic area and monitors changes in incidence or stage at diagnosis using highly standardized and structured data definitions and data structure.

### **Resources**

Central Cancer Registries in the United States by Federal Funding Source, 2010

National Cancer Institute State Cancer Profiles. <http://statecancerprofiles.cancer.gov/>

Surveillance, Epidemiology, and End Results (SEER) program <http://seer.cancer.gov/>

Tennessee Comprehensive Cancer Control Program. Burden of Cancer in Tennessee. Available at:  
<http://health.state.tn.us/Downloads/TNBurdenofCancer08.pdf>

United States Cancer Statistics (USCS) <http://www.cdc.gov/uscs>

*From Data To Action: Using Surveillance To Promote Public Health Examples*

*From the Pregnancy Risk Assessment Monitoring System (PRAMS)*

**LaTreace Harris, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention**

Established in 1987 as part of an Infant Health Initiative, the Pregnancy Risk Assessment Monitoring System (PRAMS), a Centers for Disease Control and Prevention (CDC) program, was granted congressional funding to establish state-based programs to reduce maternal and infant morbidity and mortality.

The goal of PRAMS is to improve the health of mothers and infants by reducing adverse outcomes such as low birth weight, infant morbidity and mortality, and maternal morbidity. To achieve this overall goal, PRAMS promotes collection of population-based data of high scientific quality; conducts comprehensive analyses; translates results into useable information; and builds state capacity for collecting, analyzing, and translating data. PRAMS data products instigate action and policy change on the state level and promote collaboration for state-hosted services.

PRAMS is a collaborative effort between CDC and funded state projects, covering approximately 75% of all live births in the United States. CDC leads the overall project direction and funding. State-specific modifications are coordinated by the states and can make use of other projects for additional resources. PRAMS data collection methodology is based on Don Dillman's Total Design Method, which uses a standardized data collection system and multiple contacts through mailed surveys and telephone follow-up (16).

The PRAMS population of interest is resident mothers who deliver live infants during the survey period, 2–6 months postpartum. Birth certificate files are the source of the sampling frame. The data

collection instrument, PRAMTrac, is a customized system to track data collection. The Questionnaire Data Entry System (QDES) is used for data entry, and WebCATI is the Web application used to track the results of computer-assisted telephone Interviews (CATIs). The PRAMS questionnaire comprises core questions (across all states) and state-specific questions in the form of a booklet no more than 14 pages in length. Questionnaire topics include unintended pregnancy, prenatal care, Medicaid and WIC participation, breast-feeding, cigarette smoking and alcohol use, infant health and care, and folic acid awareness. The questionnaire is available in English and Spanish and can be administered on paper or by telephone.

## *Cooperative Agreement Funding Opportunity Announcement (FOA) 101*

**Don Blackman, PhD, Extramural Research Program Office, National Center on Birth Defects and Developmental Disabilities, National Center on Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention**

Extramural research has a clearly defined life cycle, starting with the release of a funding opportunity announcement (FOA). Applicants are encouraged to read the FOA and follow the instructions carefully, keeping the following tips in mind.

1. Applicants should remember that the reviewers also will read the FOA. Reviewers will expect to read applications that address the research objectives and the review criteria.
2. Applicants should not assume that reviewers already know everything the applicants know about the research topic.
3. Applicants should be aware that reviewers will consider only information that is included in the application.

On-time submission requires electronic applications to be error free and made available to the Centers for Disease Control and Prevention (CDC) for processing from Electronic Research Administration (eRA) Commons on or before the deadline. Applications must be submitted to and validated successfully by [Grants.gov/eRA Commons](https://grants.gov/eRA).

Once the call for applications has closed, an application will receive initial and secondary merit reviews. The goal of the initial merit review is to identify projects with high scientific merit through fair, transparent, and objective reviews using panels of scientific experts. Reviewers will provide an overall impact or priority score to reflect their assessment of the likelihood for the project to exert a sustained and powerful influence on the research field(s) involved. Reviewers will look closely at the significance of the project, the credibility and ability of the investigators, the innovation of any potential product(s), the approach of the research, and the expected effect on the scientific

environment. Following the initial merit review, each application will receive a second level of review, in which a panel of CDC senior scientists will make recommendations for funding based on the scientific and technical merit of the application as determined by scientific peer review, the availability of funds, and the relevance of the proposed projects to program priorities.

FOA applicants should consider several areas that will influence the evaluation of their applications.

First, an applicant should demonstrate that sufficient time, personnel, and resources are available to make a project feasible. Second, the applicant should provide evidence that the principal investigator has the appropriate experience to lead the work. Additionally, the cumulative expertise of the research team should be adequate to complete the proposed project. The application also should include letters of support from the applicant's organization or key partners. There should be clarity and detail in the proposed research methods section. Critical resources should be described in detail, along with supporting documentation. Each application should show sufficient or more than sufficient biostatistical and analytic support, appropriate for the needs of the project. If applicable, protection of human participants should be addressed in detail, leaving nothing for the reviewer to assume. Clear presentation, easy-to-read formatting, correct grammar and punctuation, and well-organized paragraphs make reviewing applications easier.

FOAs are published to achieve public health goals. A strong application requires work and careful attention to details. FOA applications are reviewed and recommended by independent subject matter experts to ensure awards are granted appropriately to address the public health concern in question.

## ***Lessons Learned—RuSH and Other Programs***

### *Overview of Centers for Disease Control and Prevention Registry and Surveillance of Hemoglobinopathies (RuSH) Program*

**Althea Grant, PhD, MPH, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention**

The Registry and Surveillance System for Hemoglobinopathies (RuSH) is an interagency pilot project between the Centers for Disease Control and Prevention (CDC) and the National Heart, Lung, and Blood Institute (NHLBI). The first 2 years of the project will yield a hemoglobinopathy surveillance system to describe the ongoing pattern of disease occurrence and to link with public health action.

The funding opportunity announcement comprised two modules: module A was open to all states and module B was specific for any state with a high, historically underserved population. Module B states were required to meet at least one of the following criteria: 14% or more of the population had to be living below the U.S. poverty level, at least 20% of the population had to be a racial or ethnic minority, or 14% or more of the population had to be Black or African American. State governments; territories; New York City; and Washington, D.C., were eligible to apply. The project activities will include data collection and reporting, collaboration, data integration, dissemination of information, evaluation, and progress report production. The award recipient states were California, Florida, Georgia, Michigan, New York, North Carolina, and Pennsylvania. This selection of states covered 42% of all African Americans and 53% of all Asian Americans.

Year 1 collaborative activities for the project were state surveillance strategy refinement, indicator and case definition development, dataset development, data linkage, and data sharing and dissemination.

The common data sources that will be accessed and linked include newborn screening (NBS), vital statistics, Medicaid claims, and hospital discharge data. Unique data sources such as the federally-funded health and nutrition program for women, infants and children (WIC), Medicare, blood banks, and registries (such as those for cancer and immunization) also were proposed by some states.

Understanding the challenges for RuSH surveillance is key to the success of the project. Developing a disease case definition is critical to setting a common denominator. Data sharing, access, and coding validity are additional challenges that underline the need for a future validation study of this initial pilot project. Individuals not captured by NBS (most likely to be thalassemia patients and adults) are more difficult to include. To handle the challenges, three workgroups were established: (1) Data Collection and Harmonization, (2) Surveillance and Design, and (3) Community Partnerships and Health Education.

Year 2 collaborative activities will focus on data collection, analysis, and dissemination, followed by program and surveillance evaluation and data validation.

### **Resource**

More information regarding the RuSH Project can be retrieved from

<http://www.cdc.gov/ncbddd/sicklecell/research.html>.



**William Cramer, MED, Pennsylvania Department of Health**

The Pennsylvania Sickle Cell Program began in 1979 with the goal of advancing comprehensive clinical care and psychosocial support to individuals with sickle cell disease (SCD). The Pennsylvania Sickle Cell Program networks with four treatment centers and six community-based organizations (CBOs) that supplement state newborn screening mandates by facilitating and coordinating confirmatory diagnosis, treatment, and education for patients and families. CBOs integrate advocacy and assistive services to further advance disease management and help reduce crisis occurrence. The budget for the program totals about \$1.7 million a year and serves about 4,000 individuals annually. Since 1992, approximately 1,400 patients have been diagnosed with SCD through the combined efforts of newborn screening and the Pennsylvania Sickle Cell Program.

Pennsylvania is fortunate to have a number of world-renowned hematologists associated with and expanding the scope of expertise available to its Sickle Cell (SC) program and the patients and families it serves. The involvement of these specialists provides extensive knowledge and experience in the areas of pediatric and adult clinical care, as well as quality data collection and analysis. Their participation also fosters credibility among the professional community, provides an international perspective, and supports cultural diversity. Collaboration between program staff, clinicians, and CBOs to form linkages combining a variety of clinical, demographic, and health care utilization datasets for analysis and interpretation also contributes to a more comprehensive and thorough interpretation of results. Access to professional networks and research activities also ensures that patients with SCD and their families in the state benefit from the latest developments in the field.

The Pennsylvania SC Program is a practical platform for primary care physician mentorship, emergency room or department access for pain management plans, and education development and implementation. The quality of life implications are notable in that patients live better lives longer

because crisis incidence and duration is reduced, social interaction is enhanced, and recreational opportunities expanded (17). There also is an opportunity for great advancement in bone marrow transplant, development of new pharmaceuticals, and broad-based lobbying for funding.

# The California Newborn Screening Program: Understanding the Context and Approach for a Short- and Long-Term Follow-Up Data System for Hemoglobinopathies

**Lisa Feuchtbaum, DrPH, MPH, California Department of Public Health**

The state of California implemented a Web-based Screening Information System (SIS) in July 2005. SIS is a comprehensive data management system for tracking newborn screening (NBS) test results and reporting requirements. For newborns with initial positive screening results, SIS captures details of the short-term referral and case management process by which a diagnosis is confirmed or ruled out. For newborns who are determined to have a confirmed diagnosis, SIS captures selected aspects of the long-term care and management subsequently provided to the children by state-contracted specialty care follow-up centers. Two SIS data collection screens serve as the mechanism whereby center staff can upload this information to the state. The data collection elements were designed to capture the public health impact and effectiveness of the NBS program and the program's ability to prevent or minimize the morbidities and mortality associated with hemoglobinopathies among California births.

Short-term follow-up begins when a newborn has an initial positive NBS result for a hemoglobin disorder (or a metabolic, cystic fibrosis, or endocrine disorder). Working with the pediatrician of record and the family, a clinical case coordinator refers infants to a state-contracted specialty care follow-up center. New referrals are displayed in the SIS when center staff log into the system each day. During the short-term follow-up time frame, center staff enters patient service reports (SRs) each time a significant follow-up event occurs to document what tests were ordered; what services were provided; and the health status of the child at each point in time, including whether the child had symptoms indicative of one of the screened disorders. The short-term process ends when a final SR is entered indicating whether the newborn has a confirmed disorder or whether a disorder was ruled out conclusively.

If a newborn is diagnosed with one of the disorders detectable through NBS, including 25 hemoglobinopathy disorders on the California NBS panel, the individual continues to be tracked through an annual patient summary (APS) system. For any child who maintains an active status at a center, after each completed year of life (one month following the child's birthday), the state-contracted specialty care follow-up center receives an SIS alert indicating that an APS is due. When completed, the APS provides an annual health snapshot of the child, describing selected aspects of the quality of care provided and the health status of the child during the previous year of life. One APS is completed for the child each year through the time the child is 5 years of age. If, during that time, the child dies, the APS collects information about the date and cause of death, and whether the death was due to a complication of the NBS-diagnosed disorder. The APS also collects information about new diagnostic information that might have become available during the previous year; anthropometric measures of the child; health insurance status; the types of clinical services provided during the previous year; the number of appointments kept by the family; any barriers to care; the number and reasons for emergency room visits and in-patient hospitalizations; the health status of the child, including symptoms and clinical findings, disorder-related treatments initiated, and developmental concerns; and the types of referrals for additional specialty services as part of routine case management. The APS data collection form has questions specifically targeted to each type of disorder group.

The hemoglobinopathy service report (HSP) and the hemoglobinopathy annual patient summary (HAPS) forms were designed in consultation with California-based hematologists who provided their expertise to ensure that the data elements and response choices for each question are relevant and appropriate for the conditions covered by the NBS program. Lastly, the type of data being collected by California with regard to the HSP and HAPS forms will provide baseline data on hemoglobinopathies for the upcoming *Healthy People 2020* document, which was developed the U.S. Department of Health and Human Services.

**Violanda Grigorescu, MD, MSPH, Mary Kleyn, MS, Robin O’Neill MPH, Division of Genomics,  
Perinatal Health and Chronic Disease Epidemiology, Michigan Department of Community Health**

Michigan started newborn screening for sickle cell disease (SCD) in 1987. The Sickle Cell Disease Association of America (SCDAA), Michigan chapter is the coordinating center that provides comprehensive services to all newborns with hemoglobinopathies detected by newborn screening (NBS) in Michigan. SCDAA, Michigan is located in Detroit and is directed by Dr. Wanda Whitten-Shurney. SCDAA, Michigan is responsible primarily for the appropriate diagnosis of all newborns referred with positive sickle cell screening results and the initiation of penicillin prophylaxis. Sickle cell counseling and social work services are available, and each newborn has a medical home. In addition to the central office in Detroit, the program maintains offices for social workers in the cities of Grand Rapids, Benton Harbor, Kalamazoo, Lansing, and Saginaw.

The Michigan Hemoglobinopathy Surveillance and Quality Improvement Program (MiHemSQIP) has been designed as a model comprehensive surveillance system that includes cross-sectional and longitudinal data collection methods. This surveillance has not only been developed to follow a cohort of patients from birth to death (longitudinal approach), but also to understand the overall burden of SCD at different stages across the lifespan (cross-sectional approach) (18). Lifespan has been defined as a two-dimensional concept that involves recognizing that health and well-being, along with exposures and risks, occur over a continuum from conception to death (horizontal dimension), but also have an effect on offspring (vertical dimension). The horizontal dimension is comprised of longitudinal follow-up of the same cohort diagnosed at birth by NBS and cross-sectional long-term follow-up in order to assess and monitor SCD prevalence, mortality, comorbidities, service use, and costs at different stages across the lifespan. The vertical dimension applies to those of reproductive age and reflects the effects of disease on offspring.

Recommended data sources include NBS data and patient rosters for case identification; live birth records; birth defects registries; the Children's Special Health Care Services program; the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC); Medicaid; and the Michigan inpatient database (hospital discharge records). They could be used either independently or linked, depending on the surveillance objective and study question(s) to answer.

The purpose of linking NBS and birth records is to identify potentially unscreened infants, provide the Division for Vital Records and Health Statistics a method for validating data quality, and assess the feasibility of linking NBS records to other administrative databases (19). Currently, the NBS records are linked weekly with the live birth records that are received daily. SAS version 9.1 (Cary, NC) is used for data preparation, and Link Plus is used for linking. All unmatched live birth records are sent to NBS follow-up program staff. The match rate of each linkage is typically at 99% or higher. So far, all birth records since 2001 have been linked with NBS, with a goal of linking as far back as 1987 when screening for SCD first began in Michigan. MiHemSQIP is in the process of linking NBS records with Medicaid, death records for infants, and WIC data.

New collection tools have been developed, one of them being the sickle cell module within the Michigan Care Improvement Registry (MCIR). The MCIR is a Web-based system established in 1998 to track immunization, and was expanded in 2006 to include adults. Health care providers are required to report childhood immunizations to the MCIR within 72 hours of administration. A notable accomplishment is the new follow-up mechanism to include hemoglobinopathies, early hearing detection and intervention, and perinatal HIV.

Partnerships with community-based organizations and groups such as the Michigan Hemoglobinopathies Advisory Committee have been instrumental in supporting MiHemSQIP activities. The advisory committee continues to be active and instrumental in the translation of surveillance findings into actions.

Centers for Disease Control and Prevention guidelines for surveillance evaluation were considered in the design process and the expectation is that MiHemSQIP will become a good resource for identifying gaps and improving services and outcomes of the population under surveillance. This comprehensive surveillance system is being implemented and used by the Michigan NBS program to further the knowledge and address the identified gaps in the care of people with hemoglobinopathies.

### **Resources**

More information can be found at <http://www.mcir.org>.

*Ethnicity, Culture, and Immigration and Their Implications for*

*Hemoglobinopathy Surveillance in Florida*

**Phyllis Sloyer, RN, PhD, FAHM, FAAP, Children’s Medical Services, Florida Department of Health,**

**Lanetta Jordan, MD, MPH, MSPH, Director Sickle Cell Services, Memorial Healthcare System, Russell**

**Kirby, PhD, MS, FACE Department of Community and Family Health, College of Public Health,**

**University of South Florida**

Florida has one of the most diverse populations in the country. Of the 15,982,378 who reside there, 16.7% (or 2,670,794 people) are foreign born (U.S. Census). The state is home to the largest Haitian-born population in the country (182,224 individuals) and the second largest population of Jamaican-born individuals (141,182) (Migration Policy Institute). Hispanics make up 21.45% of Florida’s total population (U.S. Census). Public health surveillance can be difficult to do with undocumented immigrants because of missing Social Security numbers or other confirmed demographic information that normally would assist in linking to records from health care systems, schools, and other standard sources of data used in surveillance initiatives. With the high rate of migration in and out of the state, newborn screening (NBS) records have limited use in building a surveillance system for hemoglobinopathies for the targeted population.

Florida’s strategy for public health surveillance uses Memorial Healthcare System’s (MHS) existing relationships with community-based organizations (CBOs) to find more reliable linkages with both documented and undocumented immigrant and migrant workers. The Florida Registry and Surveillance of Hemoglobinopathies (RuSH) team has formed three advisory boards: a project oversight advisory board or steering committee, a clinical advisory board, and the community partners advisory committee. Because of the estimated prevalence of sickle cell disease (SCD) among the Hispanic population, and the large number of Hispanics residing in Florida, the state’s team has invited individuals of Hispanic descent with SCD and their family members, a program administrator for an



Hispanic university system, the health program manager for Hispanic Unity, and an Hispanic pediatric hematologist and oncologist to be a part of this initiative.

Two additional emerging populations the Florida RuSH team is focusing on are people native to Jamaica and Haiti. Church members from both communities have been invited to serve on the community advisory board. The Jamaican church leadership has hosted the Florida RuSH team's surveillance epidemiologist to speak to the church board, and board members have expressed interest in participating by inviting Memorial Healthcare System to participate in a health fair in which members of the church were screened for sickle cell trait.

The community advisory board comprises 24 members, including church leaders, a diverse group of culturally specific CBOs, physicians, specialty clinicians, social workers, government representatives, and parents of sickle cell patients. The advisory board's first meeting yielded good suggestions for improving the functionality of a surveillance project for hemoglobinopathies, such as SCD public service announcements (PSAs); recruiting a recognizable spokesperson for SCD; finding creative ways to dispel the myths about SCD being an African-American disease; and giving presentations at churches, Hispanic universities, and Hispanic organizations to spread awareness. Since the start of the advisory board, several thalassemia patients have been added to the board.

The community partners committee discussed suggestions and concerns at their meeting, noting the lack of adult sickle cell providers, specifically hematologists and primary care providers. Many providers are no longer accepting sickle cell patients into their practices. There is hope that the new Sickle Cell Center in Lakeland, Florida, will be a good opportunity for outreach. However, there is still concern that patients will not want to share identifiable data as part of a surveillance study. There is a need for more updated educational materials about SCD for diverse populations, such as the Creole-speaking community. The community partners committee also identified barriers to care, such as inadequate knowledge about SCD; limited access to primary and specialty care, particularly for the

uninsured; and very few providers willing to accept sickle cell patients secondary to inadequate insurance and the challenges of caring for adults with SCD.

Clinical committee members express excitement about the RuSH project eagerness to participate. The Florida RuSH team is creating a secure website for providers to input information on their hemoglobinopathy patients. This committee will be provided aggregate data that will be used to help identify gaps in care and services and be an impetus to change practice patterns.

The Florida RuSH team plans to use the RuSH project to identify areas where there are large immigrant and emerging populations. Hospital discharge records will identify patient country of birth, as well as race and ethnicity; these records also will identify insurance status. This will allow the group to observe any correlations between ethnicity, race, or nationality, or any combination thereof, with insurance status. This information then will be shared with members of the community partners committee. Once these community-based organizations and state-funded outreach coordinators are able to identify the specific needs of the populations in their respective regions they will be able to focus on assisting them with obtaining the appropriate insurance and finding a medical home. For instance, if a CBO discovers that it has a Haitian sickle cell population in its region, the CBO will know that it will need Creole educational materials, as well as a staff member who speaks Creole, and it then can identify providers in the area that speak Creole or have a staff member who does available. Florida's diverse population creates unique opportunities in public health to establish hemoglobinopathy surveillance, eventually leading to increased awareness, programs, education, and services.

## *Building Statewide Relationships*

### **Daisy Morris, North Carolina Sickle Cell Syndrome Program**

The North Carolina Sickle Cell Syndrome Program (NCSCSP) and the governor's appointed North Carolina Council on Sickle Cell Syndrome and Related Genetic Disorders were established in 1973 through state legislation—House Bill 32. The program is part of the Department of Health and Human Services (DHHS), Division of Public Health and offers comprehensive clinical and care coordination services for individuals affected by SCD and their families.

Unlike most states, the foundation of the NCSCSP is based on legislative mandate, requiring state legislature support, program support within DHHS, financial support, and a strong and committed advocacy council with political involvement from stakeholders for program stability. The NCSCSP provides education and genetic counseling for the general public. It also provides screening, counseling, care coordination, medical care, and payment of medical services (POMS) for eligible individuals with SCD. Care coordination encompasses case management for clients throughout the lifespan, coordination with health providers, referrals to other social and support services, and intervention for education and employment. Medical care includes comprehensive sickle cell medical treatment, client inclusion in national research studies, and community health consultations. Additionally, the POMS program assists with medical costs for eligible clients for both outpatient and inpatient services, emergency department visits, medications, medical equipment, and dental services. The NCSCSP also offers educational tools for clients and their families, and training for health care providers, faith-based entities, schools and community groups.

The 15-member governor-appointed North Carolina Council on Sickle Cell Syndrome and Related Genetic Disorders was established to advise the NCSCSP on the needs of people with SCD and related disorders and to educate the public about SCD, related blood disorders, and sickle cell trait. This governor's appointed council is composed of members of the North Carolina General Assembly,

people or relatives of people with SCD, community-based organizations, medical center representatives, and other interested groups such as the American Red Cross.

In summary, the NCSCSP and its council represent a successful model of community partnership integrated into a public health structure. This partnership has increased opportunities for sustainable community engagement and improved SCD services.

### *Working Together in Georgia and Beyond*

#### **Jim Eckman, MD, Emory University School of Medicine**

The Georgia Sickle Cell Collaboration (GSCC) was initiated in 1979. The primary impetus was a Health Resources and Service Administration (HRSA)-funded state genetics grant. The GSCC's initial goal was to improve sickle cell services. It continues to function after more than 30 years of productive collaboration.

In the same year as the establishment of the GSCC, the Sickle Cell Task Force was launched as a partnership between all providers of sickle cell related services (e.g., Medical College of Georgia, Emory University Genetics, Sickle Cell Foundation of Georgia, and Grady Sickle Cell Program). The Sickle Cell Task Force began making progress when newborn screening became a clear focus for future collaboration and roles were defined for each entity of the task force based on expertise and interests.

The roles for the Georgia Hemoglobinopathy Newborn Screening Program (GHNSP) are categorized into four focus areas: 1) the Department of Human Resources is responsible for implementing and monitoring legislation, rules, and regulations; 2) the State Public Health Department laboratory division is responsible for delivering a free screening and testing program; 3) the State Public Health Department newborn screening nursing staff is responsible for genetic counseling and care coordination; and 4) the State Public Health Department Genetics Program is responsible for data collection and program monitoring. Within the GHNSP, the Sickle Cell Foundation of Georgia (SCFG)

coordinates counseling, family education, and family testing of sickle cell trait carriers born in the Atlanta metropolitan area. The follow-up procedures include written notification to parents indicating their infant tested negative for abnormal hemoglobin, community outreach and education, and patient referral for psychosocial support services. The Georgia Comprehensive Sickle Cell Program (GCSCP) at Grady Hospital and the Georgia Health Science University (GHSU) in Augusta are responsible for follow-up of individuals with SCD. The GCSCP focuses on the Atlanta metropolitan area and GHSU on the rest of the state of Georgia.

Beyond the scope of the GSCC is the Southeastern Regional Genetics Group (SERGG), comprising Alabama, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, and Tennessee. One of SERGG's tasks was to clearly define the Technical Assistance for Sickle Cell Screening (TASCS) program to each of the member states. The TASCS program was initiated to promote universal newborn screening, assist in implementation of programs, and evaluate effects and outcomes of programs. Similar to the GSCC, the SERGG TASCS program needed to establish realistic assessment of capabilities of states and their partners, while recognizing limitations. The TASCS program was successful in helping all states in the region receive federal funding for their programs. All states represented in the region, with the exception of Georgia, rapidly implemented universal screening for hemoglobin disorders. Georgia had a statewide targeted program until 1999. An outcomes assessment was completed in Georgia, Mississippi, and Louisiana that documented positive outcomes for infants detected in the screening program.

There are meaningful lessons to be learned from the GSCC, such as mutual respect among programs, realistic assessment capabilities, presenting honest intentions of each entity, and dialogue between partners. The GSCC has been a successful model for building capacity and long-term relationships in the development of sustainable efforts to improve sickle cell services.

## *Resources for Establishing, Expanding, and Enhancing programs*

### *Data Sources for Population Surveillance on Hemoglobinopathies*

**Scott Grosse, PhD, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention**

Population surveillance of hemoglobinopathies requires reliable data sources on occurrence of disease. Clinical data, survey data, administrative datasets, and vital records are sources to consider for hemoglobinopathy surveillance. Clinical data include medical charts, clinic databases, and patient registries. Survey data are more useful for common diseases than for rare diseases. Birth and death certificate data are more helpful for common diseases. Patient registries for rare diseases may also be used as disease registries for epidemiologic surveillance and clinic-based registries. Disease registries are useful in estimating incidence and prevalence. Cases in disease registries are identified from multiple sources and can be used to de-duplicate cases. Records can be reviewed to validate or confirm cases. Clinic-based registries contain data from specialized clinics that periodically enter data on patients and can be useful for monitoring individual outcomes and evaluating treatments (20).

Multiple sources of data can build a comprehensive and reliable surveillance system by using existing administrative and clinical data sources, collecting original data, and ascertaining the completeness of cases. Complete cases can be ensured through capture–recapture methods, and a pair-wise comparison of cases assessed by type of source. Identifying the percentage of unique cases detected from each source and estimating the number of cases missed by each source also can contribute to case completeness.

Administrative data sources such as hospital datasets, health insurance claim datasets, and vital records can be linked, unlinked, or used as sources to populate patient registries (21). Data sets for surveillance can include *International Classification of Disease, Ninth Revision, Clinical Modification (ICD-9-CM)* coding. The *ICD-9-CM* has been used in United States health services data since 2004, and

the current version has codes for hemoglobinopathies. The *ICD-10* has been used in United States death records since 1999 and will be used in clinical records beginning in October 2013.

Some of the challenges using unlinked administrative data for case ascertainment are that health services data use the same codes used for screening or diagnostic testing, making it difficult to know if a patient was diagnosed or simply screened. Underlying conditions might not be recorded and codes might be applied inconsistently in health services datasets. Providers and billing clerks might be unfamiliar with specific hemoglobinopathy types, and thalassemia lacks differential *ICD* codes. Death certificate coding depends on the medical examiner, and sickle cell disease (SCD) and thalassemia likely are underreported.

Algorithms for using administrative data for SCD case ascertainment are developed using claims data by pooling *ICD-9* codes with multiple years of data. When using SCD *ICD-9* codes, it is recommended that one inpatient admission with an *ICD-9* code and two or more outpatient claims more than 30 days apart be used because outpatient codes are less reliable than inpatient codes, and diagnoses can be ruled out (22). Thalassemia *ICD-9* and *ICD-10* codes result in over ascertainment. There should be a combination of procedure and drug codes to identify transfusion-dependent thalassemia.

A data source with reliable information on diagnoses to identify cases should be the starting point to start linking datasets. Next, other data sources can be linked to assess use of health services or outcome. Private health insurance databases are also viable sources. Employer-sponsored insurance is 85% of the private insurance market. MarketScan® commercial research databases cover about 30 million people; there are also Ingenix, Inc. and other private insurance databases. Individual plans or firms can link data if individual identification information is provided to them. The health plan can create a deidentified database that provides information on health services used by plan members with a disease identified by the registry.

Among the many opportunities for linking databases, linking two or more administrative databases on the basis of common identifiable information is easiest to accomplish. Linking clinical registry databases to administrative data using individually identifiable information might be more valuable because of the reliable case definition in clinical data, but there could be concerns about privacy and confidentiality.

In addition to accessing datasets to create deidentified analytic files useful for identifying people with conditions such as SCD or thalassemia, researchers can use such files to track health care use and outcomes over time for groups of people with specific conditions. By so doing, a virtual patient registry can, in effect, be created. A challenge, though, is that claims data are subject to attrition when people change health insurance plan coverage. Many states are in the process of creating *all payer claims databases*, which can allow monitoring of health care use based on *ICD* codes at the population level, regardless of insurer (excluding Medicare) (23).

### **Resource**

Delea TE, Hagiwara M, Thomas SK, et al. Outcomes, utilization, and costs among thalassemia and sickle cell disease patients receiving deferoxamine therapy in the United States. *American Journal of Hematology* 2008;83:263–270.



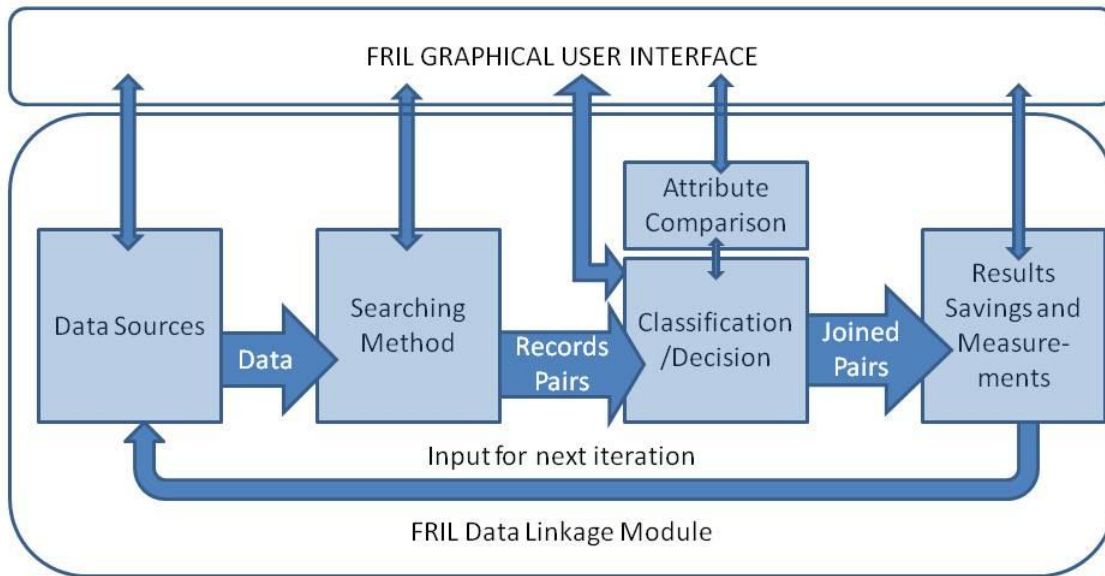
## *Record Linkage and Fine-grained Record Integration and Linkage Tool*

**Liyue Fan, Math and Computer Science Department, Emory University**

Record linkage is the process of finding records that refer to the same entity in two or more files, coreferent with duplicate detection and record matching. Decision rules are created when a pair of records is considered a match and weights identify important attributes. Search methods pair records to compare. Challenges arise when there are file format mismatches, schema (metadata) heterogeneity, data heterogeneity, or a combination thereof. Existing linkage tools, such as Link King, LinkageWiz, and LinkPlus, offer limited options for schema reconciliation, limited control over linkage parameters, and no assistance for user decisions.

The Fine-grained Record Integration and Linkage (FRIL) tool has advanced schema reconciliation, no requirements for pre-processing, a rich set of user-tunable parameters, and tools that support user decisions. FRIL provides dynamic visualization of partial linkage and automatic parameter suggestions. An application of FRIL was used to link Metropolitan Atlanta Congenital Defect Program data with the state of Georgia's birth certificate database. The former contains 12,700 and the latter 1.25 million records; 99% precision and 95% recall were reported. In the future, users hope to link records from more than two sources and include a data transformation module to address privacy issues.

# FRIL Workflow



## Resource

Fine-grained Record Integration and Linkage Tool (FRIL) <http://fril.sourceforge.net/>

**Sharon Cox, PhD, Muhimbili Sickle Cell Disease Program**

Originating in tropical Africa, Asia, and the Mediterranean area, hemoglobin disorders are among the most common inherited blood disorders (24). Approximately 60% to 70% of births affected by hemoglobinopathies occur in sub-Saharan Africa, where an estimated 224,200 infants are born annually with sickle cell disease (SCD) (25), the majority of whom die before the 5 years of age (26). The United Republic of Tanzania is estimated to have the fourth highest number of affected births in Africa. Estimates suggest that 50% to 90% of children born with SCD in sub-Saharan Africa die during childhood (27). Inexpensive interventions, such as pneumococcal vaccination and penicillin prophylaxis, have had dramatic effects on mortality in high income countries (28), but these rely on early diagnosis from newborn screening to be maximally effective.

The Muhimbili Sickle Cohort in Dar-es-Salaam, Tanzania, was established in 2004. Over 2,000 patients with homozygous (HbSS) sickle cell anemia have been identified, allowing for a description of the spectrum of disease, including mortality and morbidity due to malaria, bacterial infections, and stroke. A newborn screening (NBS) pilot in Muhimbili National Hospital (MNH) recruited infants from deliveries and admissions to the MNH neonatal ward. The nursing staff recruited mothers at a high consent rate of 96.7% of the 2,179 who were approached; 2,108 samples were collected from infants and results were obtained for 2,070 of these 2,108 infants. The prevalence of HbS (HbAS, HbSS) was 14%, and 11 children with HbSS were identified. All children returned for enrollment into the Muhimbili Sickle Cohort, with the exception of one who died before enrollment. The 2,070 results were communicated to the families via written reports that were available at the hospital, and counseling was given to parents of children with HbS (HbAS/HbSS); 78% of families were informed of the results while still in the ward, 18% of parents were contacted by telephone, less than 1% of parents were notified by a home visit (if HbS), and 3.4% of families were unreachable.

Establishing laboratory capacity for SCD testing is a critical step for NBS program. The scaling-up efforts will support the infrastructure for national reference laboratories and basic health facility laboratories at different levels of health care. There is existing capacity within Muhimbili that will be strengthened by the NBS program. Further capacity will be developed within hospital laboratories or the National Blood Transfusion Services, or both.

NBS in Tanzania will screen children from birth through 3 months of age to identify those with SCD. The program will continue to develop in three phases. Phase 1 will describe the process for screening to be conducted in Dar-es-Salaam in three hospitals with the highest prevalence of sickle cell anemia: Muhimbili, Mwananyamala, and Amana. Phase 2 will outline how Kilimanjaro, Mwanza, and Shinyanga regional hospitals will explore partnerships with the National Blood Transfusion Centers. Phase 3 will build upon the existing structure to establish NBS at the national level, where most of the effort will be focused on staff training, retaining, and dispersion across Tanzania.

NBS costs in Tanzania are the most challenging aspect of program development. Total costs can exceed \$155,000 for 40 affected births at the Muhimbili Hospital alone. The estimated projected cost of basic comprehensive care at MNH exceeds \$334,000. Funding solutions have been considered to drive down costs by taking a joint-thinking approach to managing facilities, staffing, and communicating the benefits to communities and stakeholders. Buying power and the ability to invest in new technology also is highlighted in this project. Other challenges are logistics, feedback, and data infrastructure. With no postal addresses, and limited literacy among the population, mobile phone technology might offer favorable outcomes, considering 90% of patients now have access to a mobile phone.

## **Resources**

Beyond National Borders: A Global Perspective on Advances in Sickle Cell Disease Research and Management, and New Challenges in the Genome Era (S F Ofori-Acquah & K Ohene-Frempong) in Renaissance of sickle cell disease research in the genome era. Ed BS Pace, ICP, London 2007.

## *Organizing Newborn Screening for Sickle Cell Disease: Brazil*

**José Nelio Januario, MD, Diagnosis Support Center of School of Medicine, Federal University of Minas Gerais, Brazil**

The National Brazilian Newborn Screening Program for sickle cell disease (SCD) was implemented in June 2001. Prior to 2001, most Brazilian southern state health administrations, including Minas Gerais, have organized newborn screening (NBS) programs for phenylketonuria and congenital hypothyroidism.

There were 2.9 million live births in Brazil in 2009. From that total, 1.9 million children in 14 states (out of 27) participated in NBS for SCD, which represented 64% of the newborn Brazilian population in 2009.

Approximately 1,800 new SCD cases are reported each year in Brazil. In Minas Gerais state, a total of 2.9 million infants have been screened for SCD during the last 11 years. A single reference laboratory for all states (20 million inhabitants) processes about 1,100 samples a day and 250,000 pediatric samples a year. High performance liquid chromatography (HPLC) testing is performed on each sample, followed by immunoelectrophoresis (IEP) testing on positive diagnostic results.

The performance measures system tracks the process from sample collection (at the fifth day of life) to the laboratory testing and follow-up. Newborns with SCD typically are scheduled for their first follow-up appointment by 45 days of age. The follow-up network works as an integrated system involving the Center for Newborn Screening and Genetic Diagnosis (NUPAD), state blood centers, and health centers under county administration. Out of the 2,076 patients with SCD in Minas Gerais identified from NBS through 2009, 1,841 were in a public program treatment, 23 were in a private program treatment, 61 transferred to another state program or the family changed residence, 6 had treatment interrupted by their families, and 145 died.

Education and training are important for NBS program development. The Center for Education and Aid on Hemoglobinopathies (CEHMOB-MG) offers a toll-free hotline 24 hours a day, 7 days a week for patients, advocates, clinicians, and the public. The Brazil–Africa Cooperation Project trains technicians and serves as a mentoring program for new and growing NBS programs.

## *Linked Newborn and Antenatal Screening Program in England*

### **Allison Streetly, DrPH, National Health Service Sickle Cell & Thalassemia Newborn and Antenatal Screening Program**

In the United Kingdom, the National Screening Committee makes policies and recommends screening programs to ministers. Ministers make the decision to support or not support implementation and in 2000 recommended the establishment of a linked newborn and antenatal screening program for sickle cell and thalassemia recommendations. The mission of the program include objectives to help people make informed decisions during and before pregnancy, to improve infant health through prompt identification of affected babies, to provide high-quality and accessible care throughout England, and to promote greater understanding and awareness of these diseases through the value of screening. The National Health Service (NHS) Sickle Cell and Thalassemia Program is committed to measuring and demonstrating how newborn screening (NBS) can lead to optimal outcomes, smooth the transition from screening to care, facilitate high-quality networks for care, and drive quality improvements in screening.

Although screening is a notable accomplishment, diagnosis and enrollment in care are needed to ensure children receive optimal care. Challenges to enhancing the NBS program vary and are not limited to policy development and endorsement, data collection standards, and funding. Areas such as information technology lack the support for proper translation of health information to end users. Education and training are critical and should not be overlooked. More work needs to be done with the media and community-based organizations to get communities engaged and increase their willingness to accept screening, especially antenatal screening practice. Quality assurance requires further development and evaluation should be ongoing.

Future challenges can be overcome with widening availability of resources, expansion of services, and integration across screening programs. A clear vision and well-constructed plans require leadership

and strong partners. An open advisory structure makes recommendations and constructive feedback readily available with evaluation tools and response plans. Commitment to the mission and vision, along with excellent project management skills, can bring the NBS project goals within reach.



## *Fostering and Encouraging Partnerships*

### *Evaluating Community Partnership Effectiveness*

**Jan Jernigan, PhD, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention**

Community partnerships provide a collaborative and integrated approach for developing and implementing state plans, as well as promoting policy and environmental changes to address identified health issues. Partnerships achieve these goals by acquiring and maintaining new and existing linkages, building resources and expertise, promoting networking and sharing of information, collaboratively planning and coordinating activities, providing technical assistance and training, and engaging in advocacy and evaluation activities (29).

Evaluation of partnerships is critical to monitoring progress, increasing awareness, and reaching objectives. Evaluation can serve to improve partnership functioning and productivity, leverage resources and support, provide accountability, inform partner decision making, and determine if goals and objectives are met. However, partnership evaluation does not come without certain challenges, including the fluid and evolving nature of partnerships, as well as the often unrealistic expectations of a partnership and its accomplishments (30). It is critical that evaluation be built into the planning of any partnership, that evaluation evolves as the partnership matures and grows, and that the expectations of the evaluation be realistic and informative.

Good partnership evaluations should consider three important components: 1) the purpose of the partnership, 2) the stage of partnership development, and 3) the factors that affect partnership success.

Partnerships exist for a number of reasons, including networking, collaboration, planning, and project implementation (31,32). The purpose of the partnership drives the activities and products considered

in an evaluation and sets realistic expectations for outcomes that might be evaluated. For example, the purpose of a networking partnership might be to learn new information and forge new contacts, while partnerships formed for specific projects might be engaged in leveraging resources and implementing project activities. The purpose of partnerships determines activities and outcomes that serve as the foundation for an evaluation.

Often, partnerships can be considered in three stages of development: the formative stage, when partnerships are just developing; the building or implementation stage, when partnerships are solidifying and beginning to work toward identified goals; and the maintenance stage, when mature partnerships focus more on achieving outcomes and ensuring sustainability (33). These stages affect the factors that should be considered when evaluating a partnership. Evaluation of partnerships in the formative stage should focus on relationships, leveraging resources, and expanding the partnership's sphere of influence. Evaluation at this stage can include assessing needs of the partnership; defining the vision, mission, and core strategy of the partnership; and recruiting appropriate members. The building stage of the partnership emphasizes increased collaboration, as well as engaging and building committed partnerships. Evaluation of the building stage of a partnership includes training of partners and ensuring that processes such as communication, decision making, and reporting are in place. Building partnerships encompass developing infrastructure and capacity and fostering commitment. These activities should serve as the basis of the partnership evaluation during its building stage. As a partnership matures and moves into a maintenance stage, efforts are geared toward achieving objectives and promoting the awareness and success of the partnership. An evaluation at this stage should focus not only on the progress the partnership is making toward achieving stated goals and objectives, but also on maintaining critical processes such as effective communication and leadership, as well as accountability and reporting. A number of resources and tools are available to assist with effective partnership evaluations.

Community partnerships are effective strategies for addressing public health concerns. There are benefits and barriers to the community partnership approach. However, a well-designed evaluation plan can help to identify factors that can affect the success of the partnership.

### **Resources and Assessment Tools**

Coalition Effectiveness Inventory (CEI)

Collection of partnership assessment tools ([http://www.coalitioninstitute.org/Evaluation-Research/Coalition Assessment tools.htm](http://www.coalitioninstitute.org/Evaluation-Research/Coalition%20Assessment%20tools.htm))

Evaluation Assessment Tool <http://www.uwex.edu/ces/pdande/evaluation/evalinstruments.html>

Meeting Effectiveness Inventory (MEI) (<http://coalitionswork.com/resources/tools/>)

Partnership Self Assessment Tool (<http://www.partnershiptool.net>)

Wilder Foundation's Collaboration Factors Inventory ([http://surveys.wilder.org/public\\_cfi/index.php](http://surveys.wilder.org/public_cfi/index.php))

## *Global Health at CDC*

### **Rubina Imtiaz, PhD, National Center for Global Health, Centers for Disease Control and Prevention**

The Centers for Disease Control and Prevention's (CDC) Center for Global Health (CGH) is dedicated to the health, safety, and longevity of people around the world through leadership and expertise in public health practice. The CGH is responsible for a wealth of knowledge and expertise. A cadre of technically oriented public health staff is deployed internationally and works with ministries of health to improve public health policies, services, and capacity through translational, implementation, and operational research. The CGH maintains an internationally recognized reputation as a respected, reliable, and responsible public health partner based on expertise in workforce strengthening and emergency response. Linkage to U.S. public health science and practice infrastructure allows the CGH to bring best practices to the international community through surveillance and strategic information systems. The long-standing and productive partnerships with multilateral health organizations, such as the World Health Organization (WHO), make the CGH an impressive public health entity.

A number of partnerships and programs assist the CGH in accomplishing its goals. One example is the President's Emergency Plan for AIDS Relief (PEPFAR), the largest international health initiative in history dedicated to combat a single disease. The Reauthorization Act recognized CDC's key contributions to PEPFAR and outlined the mandate to lead program monitoring, evaluation, and operations research, as well as conduct and expand biomedical research, health care technology, and health services research. Primary PEPFAR strategies include transition from an emergency response to promotion of sustainable country programs and strengthening partner government capacity to lead the response to epidemics and other health demands. PEPFAR also focuses on integrating and coordinating HIV/AIDS programs with broader global health and development programs to maximize

the effect on health systems. There are plans to incorporate PEPFAR into the President's Global Health Initiative.

Another partnership is with the Division of Global HIV/AIDS, also known as the Global AIDS Program (GAP), which provides technical leadership to ministries of health and partners worldwide to expand quality HIV/AIDS care and treatment and transition these services to local ownership. GAP is committed to implementing effective HIV/AIDS prevention programs, conducting research on program effects and cost-effectiveness, and building sustainable public health systems through the development of laboratory capacity, management and information systems, and local workforce capacity. As a global presence, GAP facilitates direct funding for 43 countries, and an additional 35 countries receive technical assistance from regional offices and headquarters.

The President's Malaria Initiative (PMI) is an interagency initiative that began in 2005 to rapidly scale up malaria control interventions in high-burden focus countries of Africa. The PMI's goal is to reduce malaria-related illness and death in focus countries through wide scale deployment of insecticide-treated nets or indoor residual spraying, improved case management with artemisinin combination therapy (ACT), and intermittent preventive treatment during pregnancy. CDC's role in the PMI is to contribute expertise in strategic information (monitoring and evaluation, surveillance, and operations research), case management, and prevention.

CDC's other malaria activities develop and deploy new, improved tools to control, eliminate, and eventually eradicate malaria. In the field, strategies and tools are used to prevent and control malaria. In the laboratory, diagnostics, medicines, and vaccines are developed, tested, and analyzed. New survey and informatics applications are developed for education and information purposes. U.S. government programs develop and manage global research consortia. To help protect U.S. travelers from malaria illness and death, there are diagnosis and treatment advice resources, prevention recommendations, and outbreak investigations. CDC implements and evaluates programs through

technical leadership to U.S. government bilateral initiatives in Africa, Asia, and Latin America through global, regional, and national control programs.

CDC estimates more than 1 billion people (one-sixth of the world's population) suffer from one or more Neglected Tropical Diseases (NTDs). This group of infectious diseases warrants CDC's attention because NTDs are the source of tremendous suffering caused by their debilitating, disfiguring, and sometimes deadly effects. CDC's NTD activities focus primarily on a set of targeted NTDs that are amenable to preventive chemotherapy via mass drug administration. CDC is able to contribute to global policy and guidelines for NTD programs, conduct research to improve diagnostic and other tools needed to deliver and monitor programs, and provide technical assistance to countries and partners to build capacity and improve programs. CDC's monitoring and evaluation process shows progress towards the elimination and control of NTDs and supports additional studies to identify and develop needed tools. The United States Agency for International Development (USAID) goal for NTDs under the Global Health Initiative is to reduce the prevalence of seven NTDs by 50% among 70% of the affected population. More specifically, USAID's contributions will have a significant effect on the elimination of onchocerciasis in the Americas by 2016, lymphatic filariasis globally by 2020, and leprosy by 2020.

The Global Disease Detection (GDD) program protects the health of Americans and the global community from the spread of infectious disease and is considered to be CDC's principal and most visible program for developing and strengthening U.S. capacity to detect and respond to global infectious disease outbreak. The GDD program is responsible primarily for outbreak response, surveillance, pathogen discovery, training, and networking. The GDD global network is a public health asset in support of ministries of health, WHO, and the International Health Regulations (IHRs).

CDC's Field Epidemiology and Laboratory Training Programs—FELTP are applied epidemiology programs that work with foreign countries to develop and implement dynamic public health strategies

to improve and strengthen the public health system and infrastructure. The FELTP is modeled after the CDC's Epidemic Intelligence Service with a 2-year, full-time postgraduate training program, whereby trainees are assigned to positions that provide epidemiologic service to ministries of health.

The Sustainable Management Development Program is a capacity-building program that helps countries strengthen their health programs, policies, and systems through improved public health leadership and management. This capacity development strategy initiates an assessment of the structure in place, followed by the formation of strategic institutional partnerships and development of faculty skills in a Management for International Public Health course.

The National Center for Immunization and Respiratory Diseases (NCIRD) has provided substantial financial and technical support for polio eradication, measles elimination, the provision of routine immunizations, and the strengthening of surveillance systems. As the home for CDC's Global Immunization Program, NCIRD provides epidemiologic, laboratory, and programmatic expertise and funding support to polio-endemic countries. NCIRD is a founding member of the Measles Initiative, which, in partnership with host governments, the American Red Cross, the United Nations Foundation, and other global partners, reduced global measles deaths by 78% from 2000 through 2008. NCIRD continues to protect the gains of polio eradication and measles elimination by strengthening immunization systems in target countries to achieve high vaccination coverage and control vaccine preventable diseases.

CDC's global health activities have grown significantly in both technical and geographic areas.

Hemoglobinopathies are also a worldwide problem and work in this area is shared with and supported by CGH.

## **Resources**

Centers for Disease Control and Prevention, Global Neglected Tropical Diseases Program.

<http://www.cdc.gov/globalhealth/ntd/>

## *Newborn Screening for Sickle Cell Disease in Africa*

**Jelili Ojodu, MPH, Newborn Screening and Genetics, Association of Public Health Laboratories**

The Association of Public Health Laboratories (APHL) is dedicated to creating a healthier world through quality laboratory practice. The APHL promotes the role of public health laboratories in shaping national and global health objectives, as well as policies, programs, and technologies that ensure continuous improvement in the quality of laboratory practice and health outcomes.

The newborn screening (NBS) and genetics program within the APHL strengthens its role in the NBS community, facilitates implementation of screening practices, develops and supports policy statements, and provides input to CDC's newborn screening quality assurance program (NSQAP).

NBS is critical to understanding how much of the population is in need of treatment and education for a host of conditions. Sickle cell disease (SCD) affects millions of people worldwide and 5% of the world's population, or 300 million people, have sickle cell trait (SCT). In Africa, more than 200,000 infants a year are born with SCD, and 60% will die during childhood. Equatorial Africa has a 10%–40% prevalence of SCT, with the highest prevalence in West Africa. Scientists estimate that 15%–40% of the Ghanaian and Nigerian populations carry SCT (8).

In the mid-1990s, an NBS pilot study was implemented for SCD in Ghana. This pilot was funded by a National Institutes of Health/National Heart, Lung, and Blood Institute (NIH/NHLBI) grant and sponsored by the Ghana Ministry of Health, various hospitals in Ghana, the Sickle Cell Disease Association of Ghana, and Children's Hospital in Philadelphia, Pennsylvania (United States). The screening laboratory is based in Kumasi, Ghana, and expansion continues towards a national NBS



program. With collaboration between the APHL and CDC, more than 300,000 infants have been screened successfully, and about 2% of screened infants have SCD. More than 85% of newborns with SCD are tracked and followed up. A memorandum of understanding with Ghana was drafted to describe the cooperative relationship between five organizations and CDC for collaborative initiatives and laboratory support for SCD and other hemoglobinopathies for NBS: Ghana Ministry of Health, Sickle Cell Foundation of Ghana, Komfo Anokye Teaching Hospital, Noguchi Memorial Institute for Medical Research, Association of Public Health Laboratories, and CDC's Newborn Screening Quality Assurance Program.

In Africa, Nigeria accounts for 75% of all births affected by SCD and ranks number one among sickle cell endemic countries in Africa and worldwide. About 24% of Nigerians have SCT and the prevalence of SCD in Nigeria is 20 per 1,000 births, which equates to about 150,000 infants born with SCD each year. About 100,000 children will die annually from SCD in Nigeria alone, representing almost 80% of deaths from SCD in Africa (34).

The newborn screening initiative in Nigeria (NSIN) aims to reduce morbidity and mortality related to diseases detectable by NBS in Nigeria, using SCD as a model. The objective of the NSIN is to provide NBS for hemoglobinopathy conditions in several states in Nigeria. The initiative also seeks to provide prophylactic and comprehensive SCD management, education, and counseling to families whose children are identified with significant hemoglobinopathies through NBS. The NSIN provides support to and collaboration with area leaders to develop sustainability for NBS. In an effort to assist nationwide program development and design, the NSIN collects relevant data on feasibility and outcomes of the initiative. The NSIN's methodology is testing, tracking, and treatment. Testing comprises collection, analysis, and interpretation of blood samples. Tracking includes receiving results; reporting; and

notifying parents, hospitals, and treatment centers. Treatment is providing comprehensive management and genetic counseling.

Next steps for the NSIN are to form an NBS advisory committee of stakeholders that will collaborate with partners to finalize available resources for the initiative. There is a need to coordinate training activities with laboratory staff and nurses and determine an initiative start date. Ultimately, similar initiatives should be coordinated in other developing countries. To expand NBS practices across the world, future activities will necessitate collaboration to assist new NBS programs in developing countries with the leadership of U.S. NBS programs, CDC, and manufacturers.

### **Resources**

Modell B, Darlison M. Global epidemiology of haemoglobin disorders and derived service indicators. Bull World Health Organ 2008;86:480–7.

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**Bruce Wood, Global Health Action**

Global Health Action (GHA) is an organization that offers health leadership and management training and assists with the implementation of community health and development programs to meet the needs of underserved communities around the world. Originally named the International Nursing Services Association, “Global Health Action” better reflects the scope of its mission. The GHA believes in the power of people and communities to identify and address their own health needs and improve their quality of life. The GHA works as a catalyst to increase the knowledge, skills, and capacity of local leaders and organizations, and as a bridge to connect different groups and levels of society.

GHA leadership and management programs focus primarily on training courses in HIV/AIDS, women’s health and reproductive health promotion, and primary health care. Leadership and management course objectives include project planning; communication skills for health professionals and community leaders; and international, domestic, and specialized custom-designed workshops. GHA’s initiatives in Africa have yielded a total of more than 350 trained people from 30 countries. Significant leadership and management activities in HIV/AIDS, women’s health, and reproductive health have occurred in China, promoting national level capacity building. The GHA also has conducted community-based youth empowerment programs and workshops in the United States.

In Haiti, GHA’s Primary Health Care Initiative trains community health workers (CHWs), farmers, and birth attendants to serve their communities. Each CHW receives training in basic health care and community development: new CHWs attend an 8-week course, while current CHWs receive ongoing refresher training. CHWs improve the quality of life for the people they serve by making health care accessible and understandable. More than 1,200 CHWs have been trained, each of whom can prevent or treat 80% of all illnesses. Another example of the GHA’s success is the Haitian Goat Program, which has helped 4,000 farmers combat poverty and malnutrition. Through a 2-day workshop, the Haitian

program coordinator teaches male and female subsistence farmers the proper care and breeding of goats. The Haitian Goat Program creates a source for income for these farmers and their families, resulting in better nutrition, access to education, and improved living conditions, and serves as an economic stimulus for the communities.

In 2004, the GHA, in partnership with the Methodist Church of Haiti, was awarded a 5-year grant to contribute to the reduction of maternal and infant mortality in Petit Goave, Haiti. The project worked with one hospital, several clinics, and mobile clinics to improve the quality of prenatal, postnatal, and infant services, as well as increase the demand for these services.

Since the devastating Haiti earthquake in 2010, the GHA has been working diligently to replace and replenish vital supplies and equipment lost or used up as a result of the earthquake and its aftermath. The GHA's immediate goals are to take care of the daily needs of the key program staff so that they can serve others. Once the GHA determines the immediate health needs and priorities of the communities, they will begin to support and equip the Haitian staff and the GHA networks of community-based providers to help address the health needs and community priorities. GHA workers look forward to enabling these community-based providers to reinforce good health practices in their communities. The GHA's long-term rebuilding activities for Haiti will require training new leaders, educating women, supporting families, rebuilding health and development systems, and preparing for emergencies.

## **Resources**

Global Health Action <http://www.globalhealthaction.org>

## *Helping CDC Do More, Faster*

### **Julie Smith, National Foundation for the Centers for Disease Control and Prevention, Inc.**

The National Foundation for the Centers for Disease Control and Prevention, Inc. (CDC Foundation) is an independent, nonprofit 501(c)(3) organization that forges effective partnerships between CDC and individuals, other foundations, and corporations to fight threats to health and safety. These partnerships help CDC “do more, faster”, offering CDC flexibility and resources to enhance its effects in the United States and around the world. The CDC Foundation provides a doorway for the private sector to work with CDC to create new programs and address public health priorities. These partnerships are especially helpful for accelerating projects or addressing specific health issues that have little or no federal funding.

The partnership cycle begins with exploring opportunities based on the common interests of CDC and its external partners. CDC scientists and leaders convene with potential funding partners, and the CDC Foundation facilitates dialogue to identify common goals and determine how to achieve them. Once CDC and these funding partners agree on roles and communication needs, CDC leads the implementation of specific strategies.

The CDC Foundation often adds value to a project by using program funds to help CDC bring on fellows or engage contractors to achieve project goals more quickly. The CDC Foundation also provides avenues for CDC to arrange project-related travel or purchase necessary project equipment and supplies more efficiently. The CDC Foundation ensures accountability and transparency by managing budgets, maintaining regular reporting schedules, and communicating project successes and challenges back to funding partners.

The final two stages of the partnership cycle involve monitoring progress and evaluating effects on future partnership activities. Each project is unique, and partnerships develop in many ways, but the partnership cycle provides a basic framework to illustrate how a typical partnership evolves. A

traditional donor–grantee relationship might progress through the cycle quickly, while a more complex, multiple partner initiative might involve more steps and take more time.

The CDC Foundation currently manages approximately 200 programs with CDC in the United States and around the world. Examples include: the Universal Data Collection Blood Inhibitor study, the Bloomberg Initiative to Reduce Tobacco Use, Strengthening Disease Surveillance and Response in Central Africa, the CDC Experience Applied Epidemiology Fellowship, Bed Nets for Children, and the Viral Hepatitis Action Coalition.

### **Resources**

The National Foundation for Centers for Disease Control and Prevention Inc.

<http://www.cdcfoundation.org>

## *Developing a Community Outreach Advisory Committee: Engaging External Support*

**Kai Stewart, PhD, MPH, CHES, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention**

The purposes of public health surveillance are to assess public health status, define public health priorities, evaluate programs, and stimulate research. Key steps to establishing a surveillance program are defining the objectives and purposes of the program, considering legal issues, engaging external support, leveraging resources, and considering record linkage. Engaging external support means going beyond seeking intra-agency and interagency support for new surveillance programs or for expansion of an existing surveillance program. Opportunities should be developed to attract the support of both nongovernmental partnering organizations and the public.

Partnering nongovernment entities such as community outreach advisory committees (COAC) with agency, organizational, and public representation is another means of obtaining input regarding uses of surveillance data (35). A COAC is a diverse group of individuals with strong ties to a community or group of stakeholders. Its purpose is to provide a public forum for stakeholders to discuss issues and concerns relating to research projects that affect a specific population or community. A COAC can be used to assess and identify the needs of the community; identify local strengths, weaknesses, opportunities, and potential threats to the program; and cultivate and maintain relationships with community leaders, community-based organizations (CBOs), and civic groups.

When conducting surveillance activities that affect a diverse group of people, it is important to reflect this diversity in the COAC. Multicultural and diverse COACs can bring great legitimacy, creativity, and effectiveness to their causes (36). It can be deeply challenging to unite varied customs, values, and

working styles in service of the common goals. An effective multicultural COAC articulates a vision, conducts strategic outreach and membership development, and establishes a structure and operating procedures that reinforce equity.

A COAC can provide immediate feedback on new ideas about potential uses for a program's data and the resources needed to accomplish programmatic activities. This can be helpful in determining the feasibility of an idea and its potential for success. Formal input from COAC advisors on a regular basis can ensure the availability of support. COAC members' knowledge of surveillance data collection activities and uses for surveillance data can be critical in securing resources for a program in times when limited resources require justification for program continuation.

### **Resources**

Community Advisory Group Handbook(2009). Department of Toxic Substance Control, California Environmental Protection Agency.

Bridging the Cultural Divide in Healthcare Settings : The Essential Role of Cultural Broker Programs(2004). National Center for Cultural Competence. Georgetown University Medical Center.

Kaye, G., & Wolff, T. (1995). From the ground up: A workbook on coalition building and community development. Amherst, MA: AHEC/Community Partners.



## *Georgia Strategies for Developing a Community Outreach Advisory Committee*

### **Jackie George, Sickle Cell Foundation of Georgia**

Since 1971, the Sickle Cell Foundation of Georgia (SCFG), Inc. has provided services to individuals and families living with sickle cell disease (SCD) and other abnormal hemoglobin disorders. The SCFG was founded by Dr. Delutha H. King, Jr. and the late Dr. Nelson McGhee, Jr. to monitor sickle cell occurrences; share and advance knowledge and research with other organizations; and, of course, to improve the quality of life of those battling the disease. Today, the SCFG continues its mission to provide education, screening, and counseling to patients with SCD.

The work and mission of the SCFG can be achieved in several different ways. However, one essential component is engaging community members who are committed to reducing the effects of SCD in the areas that are served. These community members often are asked to participate on a community advisory board (CAB).

To develop well-rounded and active CABs, the SCFG focuses on involving community members (e.g., agency members, patients, family members, and policymakers) dedicated to serving the people they represent and advocating for their needs in relation to SCD. These CABs operate with common interests and goals in hopes of echoing a single voice for a multitude of people. The key factors in developing an effective CAB are to have members who function as a unified body, share a common interest, are willing to advise as needed, serve clients, and advocate for services and education.

Additionally, an effective CAB should reflect the diversity of the population directly affected by SCD.

Board members should include people of diverse socioeconomic status, race and ethnicity, culture, and gender. Individuals from varied professional backgrounds should be included, such as health care providers, parents, patients, and representatives of faith-based and community-based organizations.

The size of a CAB is dependent on the goals and objectives of the board. Some members might serve in an advisory capacity to the board, and others might be representatives and speakers to other

organizations or agencies. Regardless of size, every CAB should be connected directly to the needs of the community and actively participate in advisory roles. CABs are an efficient way to engage community members, patients, and parents, and provide them with an opportunity to participate in current activities and future goals.

## Appendix A: Learning Collaborative Agenda

### International Public Health Learning Collaborative on Hemoglobinopathies

Wednesday, November 3, 2010

7:00 – 8:00 **Continental Breakfast & Registration**

8:00 –8:45 **1. Welcome & Opening Session**

- Ravinia ABC
- Welcome, Hani Atrash, CDC
  - Program Overview, Diane Schlachter, Facilitator
  - Overview of CDC RuSH Program and Introductions, Althea Grant, CDC [p.15]

8:45-10:00 **2. Public Health Surveillance**

- Ravinia ABC
- To foster common language and understanding of surveillance*
- To demonstrate the impact of public health surveillance on programs, policies, healthcare and health outcomes*
- Overview: Paula Yoon, CDC [p.6]
  - Panelists: Christie Ehemann [p.8], Cancer Surveillance, CDC; Catherine Rice, Autism and Developmental Disabilities Monitoring, CDC; LaTreace Harris [p.11], Pregnancy Risk Assessment Monitoring System, CDC

10:00 – 10:20 **Morning Break**

10:20 - 11:40 **3. Building Statewide Community Relationships to Establish Effective Partnerships and**

Ravinia ABC **Programs**

*To understand the relationships necessary to conduct effective programs*

*To discuss strategies for initiating relationships and creating partnerships*

- Panelists: Susan Paulukonis, CA; Lanetta Jordan, FL; Jackie George, GA; Violanda

Grigorescu, MI; Belinda Pettiford, NC; Will Cramer, PA

- Moderator, Mary Hulihan, CDC

11:40 – 1:00 **4. Lunch Presentation: Community-Focused Synergy Sponsored by Sickle Cell Disease**

Ravinia ABC **Association of America and Cooley’s Anemia Foundation**

- Sonja Banks, Sickle Cell Disease Association of America
- Gina Cioffi, Cooley’s Anemia Foundation
- Announcements, Diane Schlachter

1:00 – 2:00 **5. Concurrent Sessions**

Maplewood A **A. Lessons Learned on Intersections of Public Health and Clinical Care**

*To hear and consider lessons learned on intersections of public health and clinical care*

- Integrating Public Health and Clinical Practice

Will Cramer, PA [p.17]

- Newborn Screening and Long-term Follow-up

Lisa Feuchtbaum, CA [p.19]

Maplewood B **B. Lessons Learned on Utilizing and Linking Data**

*To hear and consider lessons learned on utilizing and linking data*

- Data Linkage

Violanda Grigorescu, Mary Kleyn, and Robin O’Neill, MI [p.21]

- Fools RuSH in Where Angels Fear to Tread...Ethnicity, Culture and Immigration and Their Implications for Hemoglobinopathy Surveillance in Florida

Russell Kirby and Lanetta Jordan, FL [p.24]

2:05 – 3:05 **6. Concurrent Sessions**

Maplewood A **C. Developing a Community Outreach Advisory Committee**

*To learn strategies for developing an effective community outreach advisory committee*

*To gain a greater understanding of how to use a community outreach advisory committee for program development*

- Mary Hulihan, CDC [p.55]; Jackie George, Sickle Cell Disease Foundation of Georgia [p.57]

Maplewood B

**D. Lessons Learned on Utilizing and Linking Data**

*To hear and consider lessons learned on utilizing and linking data*

- Data Linkage  
Violanda Grigorescu, Mary Kleyn, and Robin O’Neill, MI [p.21]
- Ethnicity, Culture and Immigration, and Their Implications for Hemoglobinopathy Surveillance in Florida  
Russell Kirby and Lanetta Jordan, FL [p.24]

Ravinia ABC

**E. Lessons Learned on Multi-Partner Involvement**

*To hear and consider lessons learned involving CBOs in programs*

- Integrating Community Partners in Public Health Infrastructure  
Daisy Morris, NC [p.27]
- Maintaining Long-term Interdisciplinary Relationships  
Jim Eckman, GA [p.28]

3:05 – 3:25 **Afternoon Break**

3:25 – 4:25 **7. Concurrent Sessions**

Maplewood A

**F. Lessons Learned on Intersections of Public Health and Clinical Care**

*To hear and consider lessons learned on (1) integrating public health and clinical practice and (2) newborn screening and long-term follow-up*

- Integrating Public Health and Clinical Practice Will Cramer, PA [p.17]
- Newborn Screening and Long term Follow-up

Maplewood B

Lisa Feuchtbaum, CA [p.19]

**G. Data Sources for Hemoglobinopathies**

*To highlight administrative data sources available for hemoglobinopathies and provide information on their strengths, limitations, and availability*

- Scott Grosse, CDC [p.31]

Ravinia ABC

**H. Lessons Learned on Multi-Partner Involvement**

*To hear and consider lessons learned involving CBOs in programs*

- Integrating Community Partners in Public Health Infrastructure  
Daisy Morris, NC [p.27]
- Maintaining Long-term Interdisciplinary Relationships  
Jim Eckman, GA [p.28]

4:30 – 5:30

**8. Concurrent Sessions**

Maplewood A

**I. Demonstration of FRIL and Linkage Tool Software**

*To discuss and demonstrate a no-cost tool to assist in linking separate data sources for multiple purposes*

- Liyue Fan, Emory University [p.33]

Maplewood B

**J. Evaluating Community Partnership Effectiveness**

*To identify principles of partnership evaluation*

*To provide examples of practical application*

- Jan Jernigan, CDC [p.41]

Ravinia ABC

**K. CDC Cooperative Agreement Funding Announcement Opportunity (FOA) 101**

*To inform the general population of criteria, selection and review processes for funding opportunities announced within the Division of Blood Disorders*

- Research  
Don Blackman, CDC [p.13]
- Non-Research  
Hector Buitrago and Sheila Edwards, CDC

**Thursday, November 4, 2010**

7:30 – 8:30 **Continental Breakfast & Registration**

8:30 –8:50 **1. Opening Session**

- Ravinia ABC
- Welcome, Hani Atrash, CDC
  - Overview and Introductions, Althea Grant, CDC
  - Announcements, Diane Schlachter, Facilitator

8:50 – 11:50 **2. Resources for Large Partnership Initiatives**

Ravinia ABC *To familiarize attendees with resources available*

*To provide opportunity to get to know one another*

(includes 20  
minute break)

- CDC Center for Global Health, Rubina Imtiaz [p.44]
- Association of Public Health Laboratories, Jelili Ojodu [p.48]
- Global Health Action, Bruce Wood [p.51]
- CDC Foundation, Julie Smith [p.53]

11:50 – 1:20     **Lunch - on your own**

1:20 – 4:15     **3. Leveraging Global Partnerships and Resources**

Ravinia ABC     *To discuss challenges in establishing, expanding or enhancing NBS programs, and receive feedback from collaborative attendees*

(includes 10  
minute break)     *To explore potential partnership opportunities to establish, expand, or enhance Newborn Screening programs*

- Establishing NBS Programs, Sharon Cox, Tanzania [p.35]
- Expanding NBS Programs, Jose Nelio Januario, Brazil [p.37]
- Enhancing NBS Programs, Allison Streetly, England [p.39]

4:15 – 4:30     **4. Closing Session**

Ravinia ABC



## **Appendix B: Resources for Hemoglobinopathies**

*International Public Health Learning Collaborative on Hemoglobinopathies*

*Presentation Slides*

[http://scinfo.org/component/docman/cat\\_view/94-hemoglobinopathy-learning-collaborative?limit=5&limitstart=0&order=name&dir=ASC](http://scinfo.org/component/docman/cat_view/94-hemoglobinopathy-learning-collaborative?limit=5&limitstart=0&order=name&dir=ASC)

*Centers for Disease Control and Prevention*

*National Center on Birth Defects and Developmental Disabilities*

*Division of Blood Disorders*

<http://www.cdc.gov/ncbddd/blooddisorders/index.html>

*Public Health Webinar Series on Hemoglobinopathies*

<http://www.cdc.gov/ncbddd/hemoglobinopathies/#webinar>

*Sickle Cell Disease - Free Materials*

<http://www.cdc.gov/ncbddd/sicklecell/freematerials.html>

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