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Strategies from the Field: Health Promotion

Georgia Health Policy Center

Registry and Surveillance System for Hemoglobinopathies

RuSH

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DEPARTMENT OF HEALTH & HUMAN SERVICES · USA
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CENTERS FOR DISEASE CONTROL AND PREVENTION
NATIONAL INSTITUTES OF HEALTH
National Heart Lung and Blood Institute

Registry and Surveillance System for Hemoglobinopathies

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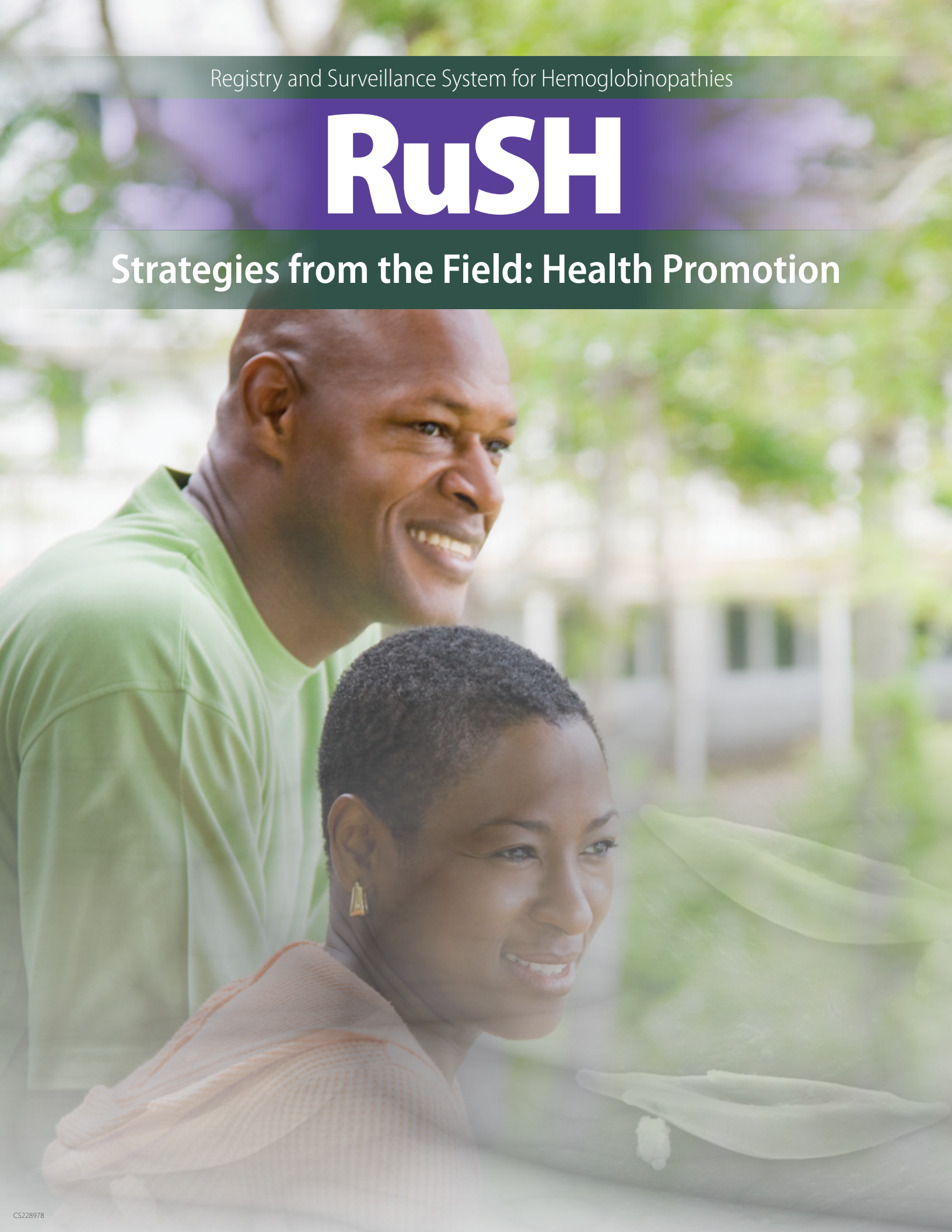

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Overview

In 2010, the Registry and Surveillance System for Hemoglobinopathies (RuSH) pilot project was implemented by the Centers for Disease Control and Prevention (CDC) to collect state-specific, population-based data on people with sickle cell disease (SCD) and thalassemia. The pilot project is being supported and conducted in collaboration with the National Institutes of Health's National Heart, Lung, and Blood Institute.

Overall project goals include determining the number of people who have SCD and thalassemia and increasing knowledge and awareness about health care use and outcomes. Currently, seven states are funded to participate in data collection: California, Florida, Georgia, Michigan, New York, North Carolina, and Pennsylvania. In addition to collecting and linking their unique data to help reach these goals, the states also have planned and implemented health promotion initiatives designed to increase awareness about RuSH in the affected communities to aid in the data collection

It is anticipated that these state-based surveillance data will:

- Provide estimates of the number of new cases (incidence) of SCD and thalassemia each year.
- Provide estimates of the total number of existing cases (prevalence) of SCD and thalassemia.
- Provide information on trends in medical care for people with these disorders.
- Provide information about complications and death rates.
- Provide information to assist with planning public health interventions (i.e., services, health promotion campaigns, health education, and training) to improve the health of these populations.

Strategy Field Reports

The purpose of this document is to showcase some of the unique ways in which the states have implemented activities designed to meet the programmatic goals of RuSH. In the following sections, each state highlights one of their many programs and features information about the resources needed to operate or replicate the activity, as well as intended benefits and outcomes, and provides a set of lessons learned to readers. Intended aims of this document are the provision of contact and programmatic information to other entities for the potential modification or replication, or both, of activities. Additionally, this document can be used to inform and motivate appropriate community members in the creation of a supportive environment for the RuSH program to assist the program in moving forward.

The information in this report was provided by programmatic team members who worked with CDC staff in fall 2011. This document comprises the following RuSH health promotion strategies from the field:

- Putting the Focus on Sickle Cell: Northern California's Focus Group and Stakeholder Meetings
- Resource STREET: Sickle Cell Disease and Thalassemia Resources To Educate and Empower the Community An Online Database Serving Southern California
- Connecting the Dots: Building a Provider Network and Directory in Florida
- Finding Our Voice: Creating and Implementing a Community Speaker Panel in Georgia
- Measuring Michigan's Health: A Hemoglobinopathy Health Status Assessment
- Garnering Statewide Support for RuSH: Regional Provider Meetings in New York
- Faith-based Initiative: North Carolina's Approach to Community Outreach for Hemoglobinopathies
- Answering the Call: Pennsylvania's Toll-Free Telephone Number for Hemoglobinopathy Health Care Referrals

The RuSH program will conclude in September 2012. Development of a strategies document highlighting surveillance activities conducted by the participating states is in progress.

Putting the Focus on Sickle Cell: Northern California's Focus Group and Stakeholder Meetings

Program Overview

Individuals with hemoglobinopathies, specifically sickle cell disease (SCD) and thalassemia, face significant barriers accessing health care services and participating in public health and clinical research projects. These barriers are related, in part, to the cultural and linguistic diversity within the affected populations and mistrust between clients or patients and providers, as well as social and economic barriers. These barriers call attention to the need for increased sensitivity and communication surrounding the initiation of new studies and projects that might offend or stigmatize the targeted population. To address these issues, the Northern California RuSH education and outreach team designed focus groups and stakeholder meetings to address the effects of RuSH on the SCD and thalassemia communities. The primary objective was to obtain input from stakeholders through focus groups on how to (1) engage the SCD and thalassemia communities with the RuSH project, (2) address potential barriers to hemoglobinopathies surveillance, (3) assess the appropriateness and appeal of the RuSH messaging tools, and (4) identify additional community stakeholders who should be engaged with the RuSH project.

Resources Needed

Qualitative data and clinical research expertise was used to help design a script for the focus groups that addressed the objectives. A standard definition of the terms "surveillance" and "registry", and examples of each, was presented to the groups. Established community connections were used to compile the invitations for initial focus group meetings. To solicit participation in future focus groups, stakeholders were asked to identify additional community contacts.

A convenient and comfortable meeting space was reserved to host the focus group meetings. The meeting environment limited external distractions, and food was provided before the sessions began. The group facilitator led the discussions with a note-taker present, and each session was recorded using a digital recording device. The notes were reconciled with the recording transcripts immediately following the focus group meetings.

Benefits

Information gathered from the stakeholder focus group meetings is intended to provide guidance to the RuSH project about potential barriers and perceived benefits to surveillance and participation in a registry program. Feedback from stakeholders has been valuable in the design, marketing, and implementation of the RuSH project. The focus groups have allowed the RuSH project team to foster a relationship with affected communities, thereby influencing subsequent actions to be transparent and consumer focused. Another benefit of the focus groups is the opportunity to provide basic education about hemoglobinopathies to communities that might or might not be affected directly by the diseases or complications, but would benefit from targeted education.

Outcomes

To date, four focus groups of stakeholders have been convened, with a total of 34 individuals participating. Participants included the psychosocial team members of a comprehensive sickle cell center, leadership of regional SCD community-based organizations, individuals with thalassemia, and staff from the local Asian Health Services program. Participants were educated briefly about public health surveillance and asked to respond to questions about barriers to and facilitators of community participation in surveillance for hemoglobinopathies. Participants reviewed and critiqued written materials created for RuSH and identified other important groups to target, to share RuSH messaging.

Following the focus group meetings, Northern California RuSH team members reviewed notes and audio transcripts independently to identify common themes within and across groups.

The focus groups identified common themes around surveillance, which included concerns about who will have access to the data and what will be done with it, and the need to identify and communicate direct benefits to patients. Focus group members saw RuSH as a means of educating providers and the general community about hemoglobinopathies and suggested customizing materials (culture and language) for different audiences (e.g., providers, patients, communities). Perhaps the most valuable feedback identified the potential barriers to surveillance and registry data collection. Historic mistrust among targeted groups and cultural mores maintaining secrecy about the conditions were cited as major factors. Participants also provided a diverse listing of regional community health, provider, faith-based, social, and academic groups that should be approached as potential supporters of RuSH.

Lessons Learned

- 15 minutes should be allotted for general education on hemoglobinopathies at the beginning of the focus groups, especially for groups that are further removed from health care fields, such as cultural organizations, sororities, and fraternities.
- Educational materials should be clear about the potential effects of the RuSH project on research and health practice, as well as specific actions the community can take to support the RuSH project.
- Educational materials should be customized for diverse audiences, which includes taking into account various language and cultural differences, audiences and age groups.

Next Steps

The Northern California RuSH education and outreach committee continues to contact groups identified through prior focus groups to organize new focus groups, specifically with patients with SCD and local community SCD and thalassemia provider groups. Focus group results were summarized in an abstract, with plans to publish the data.

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Words from the Field

"What is going to be the benefit of participating in surveillance? Better access to care? Now, that's a true incentive!"

— Sickle Cell CBO Leader

"I hope that a program like [RuSH] will put more pressure on providers to follow the standards of care for thalassemia."

— Thalassemia Patient

"Having [a] record of cases and information about patients will show policymakers how many people are living with thalassemia and sickle cell in this country; real numbers. Right now, it's vague; they think it's really rare. Hopefully, this will make it easier for them to see what their constituents look like."

— Thalassemia Patient

Resource STREET: Sickle Cell Disease and Thalassemia Resources to Educate and Empower the Community — An Online Database Serving Southern California

Program Overview

Resource STREET is a comprehensive, online database that manages information relevant to the community outreach elements of the California RuSH project. In an effort to reach out to specific communities affected by sickle cell disease (SCD) and thalassemia, the database was created to capture and organize available resources. The database contains information about individuals active in sickle cell and thalassemia communities, community organizations, institutions, and other entities offering direct or support services to patients and their families; it does not contain patient information.

The database provides a central resource for RuSH staff in Southern California, as well as for community-based organizations that are participating in the project. There are over 18,000 providers and 4,000 organizations and institutions in the database.

The flexibility of the database allows for several things:

- Users can update information in real time.
- People or organizations can be grouped together and marked as public or private.
- Detailed information about an organization, such as mission statement, programs, languages supported, and a link to the organization's homepage can be entered.
- Information can be shown on a map (locations of providers, organizations, and other resources).
- Customized reports can be generated.
- The database allows for queries concerning usage, such as the volume of activity using each outreach method.

Resources Needed

The fundamental computer code developed for the database is available to anyone interested in building a database with similar components. A fundamental license for Microsoft SQL Server® 2008 is required. Installation and setup of the database requires assistance from the developer. Fees for developer services have to be arranged through individual contracts, and there might be fees associated with hosting the database locally or through a common provider such as Amazon.com®.

It is important to have one or two individuals who are knowledgeable about the system and able to answer questions for other users designated as data managers. The data managers ensure the accuracy and integrity of the information and oversee data input and output.

Benefits

There are significant benefits to having information in one place, immediately accessible to users, and flexible so that users can enter the information and create personalized groups. A relational database provides the ability to retrieve information in a wide variety of ways, such as:

- Providing a common repository for all contact information for individuals or organizations whose services might be of use to providers or patients with thalassemia or SCD.
- Providing the information in a normalized relational database format such that queries and reports can be generated.
- Allowing geographic localization of resources, including medical providers.
- Allowing tracking of the effectiveness of various resources and assisting hemoglobinopathy programs and patients.

By providing a central repository and allowing individuals to contribute to the database over time, the total amount of work and time spent in locating resources throughout the state can be reduced.

Outcomes

The database has been invaluable for generating mailing lists to send outreach materials, surveys, and other information to target groups of providers and organizations. The Southern California RuSH team has also been able to connect patients with resources available in their geographic area. A newly created community based organization in Southern California has expressed an interest in obtaining access to the database and using it for project management. There are plans to survey users for feedback on ease of use and functionality, and suggestions for improvement.

Lessons Learned

Database development is a trial and error process, and it is difficult to anticipate exactly how long each stage of development will take. Plenty of time should be allowed to design and redesign elements of the database, as well as for users to adapt to the new system and receive assistance. It is helpful to have personnel on call to field questions as they arise.

Next Steps

This database serves as a common repository of information to identify providers, agencies, and individuals with resources for SCD and thalassemia. Eventual implementation of a geographic mapping module will allow patients and providers to identify resources within a defined geographic area.

Use of this program with community-based organizations in California will continue. Key staff members have been trained to update the database on a regular basis, and there are plans to continue maintaining the system.

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Words from the Field

"Our Southern California sickle cell community needed a database to manage information about resources, and we're glad this project happened. We can share the information with people who are looking for resources and those new to our SC Community. As a sickle cell educator and health advocate, the database has allowed me to focus my time on other important issues for our community."

— N.T.

Connecting the Dots: Building a Provider Network and Directory in Florida

Program Overview

The Florida RuSH coalition formed three advisory committees, one of which is the Community Partnership and Health Education Committee, consisting of leaders from sickle cell community-based organizations (CBO) and state-funded sickle cell outreach coordinators. The Community Partnership and Health Education Committee discussed the need for a provider directory that would serve as a referral resource of hemoglobinopathy experts who provide care, care coordination, counseling, education, and follow-up for individuals with a hemoglobinopathy (sickle cell disease [SCD] or thalassemia).

An initial task in creating such a directory was obtaining the location of hemoglobinopathy physicians and other providers and hospitals in Florida, in addition to other pertinent information. The South Broward Hospital District (SBHD) Planning and Marketing Department obtained SCD- and thalassemia-specific data from the Agency for Healthcare Administration (AHCA), for fiscal year 2008. AHCA is the state agency that collects data on hospital and emergency room discharges, surgery, and ambulatory care centers. Information from AHCA was divided into the following categories: pediatric, adult, inpatient, outpatient, emergency room utilization, and physician. Data were assembled based on information from top volume hospitals and physicians and other providers into a Microsoft® Excel file. The directory then was shared with the Community Partnership and Health Education Committee and Florida's Children's Medical Services (CMS) hematology and oncology centers.

Resources Needed

To replicate a state- or geographic-specific physician and other provider directory, access to the state's health care inpatient, outpatient, ambulatory, emergency room, and hospital discharge data is necessary, as well as provider's disease-specific volume data. Minimal staff is needed to create and maintain the directory.

Benefits

The purpose of the physician and provider directory is to assist SCD and thalassemia patients, community-based organizations, outreach educators, and anyone in need of locating a hematologist with expertise in SCD and thalassemia. Thus, benefits include increased referrals for services and support, closing the gap between patients and services, and access to a more comprehensive care system for hemoglobinopathy patients and their families.

Outcomes

A notable outcome is the use of the tool by Florida CMS nurses whose role is to provide care coordination (case management) for CMS-eligible children from birth through 21 years of age. CMS is a Title V program that provides care for children with special health care needs through 22 CMS area offices. CMS nurses have reported that this directory has assisted them in finding adult providers for adolescent patients.

Anticipated Outcomes:

- Assists individuals with hemoglobinopathies in locating expert providers within or close to their community.
- Assists CMS area offices in connecting patients 18 through 21 years of age with local adult physicians and other providers.
- Creates a network of physicians and other providers in the state of Florida with expertise in hemoglobinopathies.
- Identifies gaps in geographic distribution of physicians and other providers with hemoglobinopathy expertise.
- Identifies gaps in service location.
- Monitors hemoglobinopathy health care usage trends.

Lessons Learned

An important lesson learned from the development and dissemination of the physician directory is that there is a greater need for such a resource than initially projected. Although the Florida RuSH coalition generated the physician directory, it was not immediately shared with the Community Partnership and Health Education Committee because the coalition was unaware of the immediate need in the sickle cell and thalassemia communities. Communication across workgroups and committee is a valuable tool that can create pathways from resources to those who need them most.

Next Steps

The next step will be the creation of a map of Florida highlighting geographic locations of physicians and other providers who treat hemoglobinopathies. Currently, Florida is reaching out to physicians and other providers to provide hemoglobinopathy patient data through a secure website, as part of the data collection activities for the RuSH initiative. When physicians and other providers sign up for the online data collection account, they will be prompted to indicate if their practice or services may be included on the map and in the directory. The option to be included in the mapping system and directory also will be offered to any other physicians or providers. All physicians and providers who are interested in this system will be verified using the Florida Department of Health Provider Search website.

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Words from the Field

"One of the biggest challenges faced by patients and families is to identify a hematologist. The physician and other provider directory will assist sickle cell disease and thalassemia patients, community- based organizations, outreach educators, and anyone else in need of locating a hematologist with expertise in sickle cell disease and thalassemia."

— Lanetta Jordan, MD, MPH, MSPH,
Director, Sickle Cell Services,
Memorial Healthcare System, Florida

Finding Our Voice: Creating and Implementing a Community Speaker Panel in Georgia

Program Overview

The Sickle Cell Foundation of Georgia (SCFG) has a long history of providing outreach and education to sickle cell clients throughout the state. To extend and guide outreach efforts, the SCFG and its partners created a speaker panel to promote the RuSH project to sickle cell disease (SCD) clients, the community, and health care providers. Five key strategies were used to create and initiate the speaker panel and will be used in the near future to train the speakers: (1) carefully select speaker panel representatives, (2) focus on creating messaging relevant to key audiences, (3) design materials for Spanish-speaking audiences, (4) use a highly regarded training curriculum, and (5) activate health care provider connections to reach additional key audiences.

Resources Needed

A variety of resources are used to implement five key strategies.

Strategy #1: Carefully select speaker panel representatives

- Data from the RuSH project is used to identify counties with high concentrations of individuals with SCD and racial and ethnic groups of interest.
- Sickle cell support groups are used to identify contacts in counties of interest.
- Existing and newly established relationships with support group leaders are utilized; leaders with a strong commitment to education and outreach are identified as potential panel speakers.
- A wide range of representatives are selected to ensure a variety of resources will be available.

Strategy #2: Focus on messaging relevant to key audiences

- A deep knowledge of SCD clients and their needs and interests helps formulate messaging.

Strategy #3: Design materials for Spanish-speaking audiences

- Staff that specialize in outreach for this audience are engaged to generate materials.

Strategy #4: Use a highly regarded training curriculum

- The Baby STEP® curriculum, created by health care specialists from the University of Alabama, Birmingham, is distributed to all speaker panelists for use in presentations.

Strategy #5: Activate health care provider connections to reach additional key audiences

- Relationships with health care providers specializing in the treatment of SCD are employed to facilitate connections with other health care providers.

Benefits

Carefully selecting panel members who are also support group leaders and crafting messages relevant to their client audiences strengthens the connection between the RuSH project outreach activities and the ultimate goal of improving outcomes for clients. Designing materials for Spanish-speaking audiences helps the speaker panel overcome language barriers. People often share health information with their loved ones, and information that already is translated and accessible is more likely to be shared. Using an existing curriculum has ensured speakers have a consistent and comprehensive resource for background information, which has increased the likelihood that accurate and appropriate information is shared with target audiences. Utilizing relationships with health care providers allows the speaker panel members to identify areas of high need throughout the state and facilitate appropriate connections for professional education and outreach.

Outcomes

Georgia anticipates 15 to 20 people will complete the training for the speaker panel in the spring of 2012. Panelists will track the number of speaking engagements, their audiences, and additional resources needed, and identify opportunities for additional panel presentations. Audiences will be given evaluation forms after participating in the panel discussions, to comment on the panel as an additional means of ongoing quality improvement.

Lessons learned

The process of developing the speaker panel has revealed that SCD clients and their families are cautious of research, just for the sake of research. Information from the RuSH project must be relevant to the needs of clients, and offer a more immediate response to their participation. Identifying speakers who understand those needs and can deliver messages that articulate the importance of improving outcomes for clients is critical to supporting RuSH and supporting clients.

Building and maintaining relationships with clients and those who serve clients through support groups and health care is essential to reaching those most in need. Translating materials from one language to another is not sufficient; there has to be a culturally relevant connection. Materials that creatively use elements of Latino culture to create stories and characters for explaining the information have been well received.

Next Steps

Moving forward, the speaker panel trainings will be held in March 2012. Creation of an evaluation form will assist in tracking the effects of the panel on audiences. Presentation posters will be designed and printed as visual aids, with detailed information and data for each target area.

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Words from the Field

"The majority of my population doesn't know what their hemoglobin is or why it's important to take the test. We educate them about sickle cell after they know about hemoglobin."

— Janeth Spurlin

"Ten years from now, I don't want to be doing the same thing. We need to make real improvement for people with sickle cell disease through education, legislation, and economic resources."

— Jackie George,
Sickle Cell Foundation of Georgia

Measuring Michigan's Health: A Hemoglobinopathy Health Status Assessment

Program Overview

Newborn screening (NBS) for sickle cell disease (SCD) has been conducted at the Michigan Department of Community Health since 1987. Longitudinal follow-up of SCD case patients diagnosed by NBS traditionally has been carried out through 5 years of age by NBS follow-up staff in collaboration with the Sickle Cell Disease Association of America, Michigan Chapter (SCDAA-MI). SCDAA-MI is a community-based organization whose contract is funded through Michigan's NBS fee to provide medical management and support to families of children in Michigan with SCD. As part of the RuSH project, the Michigan Hemoglobinopathy Surveillance Quality Improvement Program (MiHemSQIP) expanded hemoglobinopathy follow-up throughout the lifespan by enhanced monitoring of comorbidities, service use, and patient outcomes.

Michigan developed a health status assessment (HSA) to measure access to care, disease complications, health care use, financial status, and educational status among people in Michigan with SCD. The HSA provides annual self-reported information on patients, in order to learn more about Michigan's population with SCD, provides feedback on educational initiatives provided by the SCDAA-MI, and facilitates conversation among patients and their families about important health issues related to SCD.

Patient advocates employed by the SCDAA-MI work with families from the main office in Detroit, as well as four regional offices throughout Michigan, to ensure that all children with SCD are receiving proper care and services. Beginning in 2011, patient advocates included the HSA as part of their follow-up protocol for families of children with SCD. Currently, the assessment is used as a surveillance tool for case patients of all ages. Parents answer the questions by telephone or in person; patients respond for themselves if they are 18 years of age or older. Patients with SCD not detected by NBS since 1987, adult SCD patients, and those born outside of Michigan are often identified through clinic referral or word of mouth, and may be included in the HSA.

Resources Needed

Michigan's HSA questionnaire was adapted from the individual utilization questionnaire created by the Sickle Cell Disease Treatment Demonstration Program, and modified over time to specifically meet the needs of the state. Development and Implementation of the HSA would not have been possible without the SCDAA-MI or the Michigan Hemoglobinopathy Quality Improvement Committee (MiHemQIC).

The MiHemQIC provided critical insight in the development of the HSA, and continues to provide feedback on a regular basis.

Benefits

The HSA has been included as part of regular follow-up for all SCD case patients detected via newborn screening since March 2011 in an electronic, Web-based application via the Michigan Care Improvement Registry (MCIR). The hemoglobinopathy module of MCIR allows patients to be managed efficiently by SCDAA-MI staff and NBS follow-up staff, and could be expanded to include clinicians. The electronic HSA application was later launched within the MCIR module for all children 1 through 5 years of age initially detected by NBS, and has been expanded to include older children and adults, such as those who are not detected through NBS. This computerized form for self-reported or clinically verified health information allows for real-time data extraction and quality improvement. Aggregate results are available immediately to SCDAA-MI patient advocates and staff, providing valuable feedback for provision of services. Developing the MCIR module and HSA through RuSH has allowed for ongoing validation and evaluation of the assessment, with potential for significant quality improvement as the HSA is expanded to include a larger population.

Outcomes

During the first 6 months of implementation, 135 assessments were completed by patient advocates across the state. As each HSA is conducted, important conversations often occur between parents of children with SCD and SCDAA-MI follow-up staff on topics that might not have come up otherwise: vision screening, hydroxyurea therapy, nutritional supplements, and bone marrow transplants. Conversations about these issues come up naturally, allowing for an impromptu educational session during the data collection process for participating families.

Lessons Learned

The questionnaire is modified and adapted continually for quality improvement by MiHemSQIP staff as more HSAs are conducted. All involved patient advocates have agreed on and use the same questionnaire. Original plans for annual assessments were not feasible, and the MiHemSQIP currently is modifying the assessment to be conducted once every 2 years, with the first HSA being conducted with parents, in-person or by telephone when children identified by NBS are 12 months of age.

Next Steps

As Michigan continues to improve the MCIR sickle cell application, there is hope of building integrated report-making tools that will provide aggregate and individual-level data to SCDAA-MI staff.

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Words from the Field

"Our families are excited to hear about the RuSH program and eager to "stand up and be counted". We have found that the health status assessment frequently has the added value of initiating an impromptu mini education session on hydroxyurea, bone marrow transplant, transfusions, vitamin supplements . . . the list goes on and on."

— Wanda Whitten-Shurney,
Executive Director, Sickle Cell Disease Association of America,
Michigan Chapter

"Michigan's hematologists have been actively involved with every step of HSA development as part of their advisory group duties. Often, their response to content during meetings has led to vibrant conversations on specific treatment experiences related to sickle cell disease, inadvertently improving quality of care and best practices for hematology throughout our state."

— Robin O'Neill,
Michigan Hemoglobinopathy Surveillance & Quality Improvement Coordinator

Garnering State-wide Support for RuSH: Regional Provider Meetings in New York

Program Overview

The New York RuSH project team launched a community outreach program in summer 2011 to achieve one of the project's objectives: to identify at-risk populations with hemoglobinopathies in New York State (NYS). This program, a collaboration of the RuSH project team, the RuSH advisory committee, and a community-based organization—the Cooley's Anemia Foundation—focused on (1) outreach via regional meetings to community-based health care providers across the state who specialize in hemoglobinopathies and (2) administration among providers of a survey with questions about characteristics of hemoglobinopathy specialty care centers (HgbSCCs) and the degree of clinical information available regarding affected patients, including confirmatory diagnoses, comorbidities, and health care use.

Resources Needed

A survey was developed to assess the long-term health care status of people with hemoglobinopathies, identify clinical information collected at HgbSCCs, and explore the possibility of sharing and accessing collected clinical data. The brief survey, which consisted of 16 close-ended questions, was filled out by the participating health care providers at the regional meetings. It also was sent via e-mail to providers who did not attend the regional meetings. Project staff planned and conducted the regional meetings and developed and administered the survey. The cost of these activities included staff preparation time, travel, follow-up meetings with registrants and participants, meeting spaces, equipment rentals, handouts, materials, and the annual service charge for the online survey tool.

Benefits

The most notable benefits of the regional meetings were:

- Enhanced collaboration among the project team members, advisory committee members and community-based organizations.
- Opportunities for in-person interaction and relationship building between the project staff, community, and providers.
- Demonstration of the feasibility of obtaining clinical data from the HgbSCCs for RuSH.

Outcomes

A database containing 258 providers representing 63 HgbSCCs across NYS was constructed. All providers were contacted and invited to the New York RuSH regional meetings. In fall 2011, two regional meetings were conducted in the New York City area; three providers representing three HgbSCCs and six providers representing five HgbSCCs participated in the meetings in Brooklyn and Manhattan, respectively. Only five providers registered for the meetings in the upstate New York area (three in Albany and two in Syracuse). Due to low registration in this area, registrants were invited to attend a meeting in Herkimer, New York, which is located geographically between Albany and Syracuse. Unfortunately, the meeting was canceled due to travel complications following the devastation caused by Hurricanes Irene and Lee.

After the regional meetings, an email containing a brief introduction to the survey, the Centers for Disease Control and Prevention's RuSH project fact sheet, and an executive summary about the New York RuSH project, along with a Web link to the online survey, was sent to the 249 providers representing 55 HgbSCCs who did not attend a regional meeting. Two follow-up emails were sent to non-responders in 2-week intervals as a reminder to complete the online survey. Reminder calls also were made to complete the survey through a telephone interview. To date, 90 providers representing 49 HgbSCCs have completed the survey, resulting in a 78% response rate (49/63 HgbSCCs). Implementation of the regional meetings has helped achieve the main objectives of the project's outreach efforts, as well as jumpstarted fulfillment of the overall RuSH program objective.

Lessons Learned

Project staff must work closely with clinicians and staff at the HgbSCCs to facilitate the Institutional Review Board application and approval process for collecting and sharing clinical data. The process of providing all necessary documents, guidance, and assistance is labor intensive. Preparing a thorough list of essential data elements and conducting active follow-up to obtain timely progress updates are critical to successful outreach efforts with community-based HgbSCCs and providers across NYS.

Next Steps

The New York RuSH project team will continue outreach efforts with community-based HgbSCCs and clinicians who provide care to hemoglobinopathy patients across NYS. In-person regional meetings in downstate (excluding New York City) and upstate New York areas will be planned and conducted. Ad hoc webinars or teleconferences on topics of interest to collaborative participants will be organized. Project staff plan to analyze survey results and prepare a summary report to share with the HgbSCCs and the RuSH project collaborators.

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Words from the Field

"Collaboration: Key to Success for RuSH! - Case ascertainment from multiple sources/programs with collaborative efforts is a crucial step to establish a population-based registry and surveillance system for hemoglobinopathies."

— New York RuSH Project Team

"Community outreach provides opportunities for in-person interaction and relationship-building between the project staff and health care providers for effective collaboration on RuSH project."

— Dr. Ying Wang,
New York State Department of Health

Faith-based Initiative: North Carolina's Approach to Community Outreach for Hemoglobinopathies

Overview

The initial collaborators in North Carolina's RuSH program included community-based organizations and medical centers with expertise in sickle cell disease(SCD) and thalassemia, along with the Governor's Council on Sickle Cell Disease and other Related Disorders. As the program progressed, the North Carolina Community Partnerships and Health Education Workgroup formalized and developed a plan to increase awareness and education related to SCD and thalassemia in North Carolina through a faith-based initiative.

The North Carolina Faith-based Initiative (NCFI) was established in 2011 to enhance educational and outreach strategies involving key faith-based communities. The goal of the initiative is to build a systematic approach for including faith-based organizations in hemoglobinopathy awareness and education activities by:

- Partnering with governing bodies of faith-based institutions of all sizes.
- Working with the medical community for technical assistance and support.
- Enhancing faith-based partnerships through alliances with community-based organizations and regional educator counselors.
- Utilizing the Cooley's Anemia Foundation for thalassemia expertise and education materials.

Resources Needed

This project began by formalizing partnerships with statewide faith-based organizations to garner participation and support. Initial collaborations included the General Baptist State Convention of North Carolina's Center for Health and Healing and the North Carolina Greek Orthodox Archdiocese, because of high SCD and thalassemia prevalence rates among Black or African-American and Greek populations, respectively. The General Baptist State Convention of North Carolina represents over 1,700 Black or African-American congregations, and there are 13 Greek Orthodox Churches in North Carolina, all strategically located in major cities with large Greek communities.

An educational toolkit was developed, with input from various faith leaders, containing a program overview, brochures, church fans, bulletin inserts, and a DVD. A Microsoft® PowerPoint presentation for faith-based audiences also was developed and delivered by a representative of the program (i.e., sickle cell educator counselors, community-based organization members, or medical center staff). The state program's education consultant provided programmatic oversight.

Ample staff time and leadership are required to facilitate partnerships with faith-based organizations to develop the best educational approach for each organization. Partnership meetings were held to plan, coordinate, and schedule activities with key stakeholders. Staff trainings were used to develop critical messages, ensuring consistent delivery. Training expenses were attributed to staff time, travel, and conducting follow-up sessions to strengthen future programs. A toolkit of materials, general travel expenses, website postings, equipment and supplies should be considered. A significant cost savings was achieved through a partnership with the Cooley's Anemia Foundation, which provided technical assistance, educational materials, and training about thalassemia at no cost.

Benefits

The NCFI provides a consistent outreach message to faith-based organizations. SCD and thalassemia education is included in church health programs and provides a platform for a public health message. This initiative also provides an opportunity to identify new clients (individuals living with SCD or thalassemia) and those who have been lost to follow-up. The faith-based initiative creates a support system for individuals with SCD and thalassemia and is a cost-effective method to increase awareness and education through ongoing partnerships and networking.

Outcomes

Preliminary data have indicated that faith-based communities are receptive to this approach. Information gained from the participant evaluation tool was favorable, with 90% of participants demonstrating an increased knowledge of SCD and thalassemia after attending the session.

Lessons Learned

It is important to provide culturally appropriate and personalized information based on religious practices. Identifying an advocate in the faith-based setting, such as a gatekeeper or pastor, as a point of contact for the program is key for effective communication. Connecting with parishioners who are affected by SCD or thalassemia can be a way to personalize the connection with the congregation. Sustainability of the program is an important discussion to have with key leaders, so efforts do not dissolve with time or change of leadership.

Next Steps

The NCFI includes plans to expand activities to other traditional, nontraditional, and nondenominational faith-based organizations. NCFI activities will be evaluated through surveys and focus groups, evaluations, and key informant interviews. The program will examine how this project aligns with the White House Office of Faith-based and Neighborhood Partnerships to determine future opportunities for enhancement and expansion of awareness and education of hemoglobinopathies.

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Words from the Field

"We want to empower people with knowledge. We want to give information that will allow good decision- making. We want to empower people to take charge of their lives. The information that you provide allows us to give that hand up to a healthier life."

— Rev. Warren
of Little Rock AME Zion Church,
Charlotte, NC

"This type of outreach connects with one's soul, and creates long-lasting relationships; and our efforts prove that."

— Aziz Coleman,
Sickle Cell Educator Counselor, Community Health Interventions and Sickle Cell Agency

"The presentation to our women's group on thalassemia was very educational. It answered questions that people thought that they had the answers to but were wrong. Now they are giving the right information to their daughters, nieces, and other relatives."

— Ann-Marie Dentiste,
Chapter President, Ladies Philoptochos Society, Annunciation Greek Orthodox Church,
Winston-Salem, NC

Answering the Call: Pennsylvania's Toll-free Phone Number for Hemoglobinopathy Health Care Referrals

Program Overview

One of Pennsylvania's goals is to provide a mechanism to directly reach individuals with a hemoglobinopathy diagnosis. The unique partnership between the Pennsylvania RuSH Team, hospitals, and community-based organizations has resulted in a collaboration to establish a toll-free number (1-855-4SICKLE) that allows individuals with sickle cell disease (SCD) or thalassemia to connect with regional community-based programs and comprehensive hemoglobinopathy programs, and enroll in appropriate care, as well as the state hemoglobinopathies database.

Following a greeting and brief explanation of the purpose of the toll-free number, callers will be prompted to use their touch-tone key pad to indicate whether they have SCD or thalassemia and to enter their ZIP Code. Calls will be routed to the community-based organization (CBO) that is best prepared to service the ZIP Code indicated. CBOs will use a script and intake form that includes questions to ascertain contact and demographic information; diagnosis and current source of medical care and insurance; and how the caller heard about the toll-free number. The contacted organization also will coordinate referral appointment scheduling and, when necessary, provide someone to accompany the individual to the appointment.

Callers after business hours will be prompted to leave a call back number, which will be retrieved and returned on the next business day. Aggregate descriptive data of the toll-free number use will be obtained and each organization will report to the Pennsylvania Department of Health with information obtained through the call script and intake form and the outcome of health care referrals.

Resources Needed

Flyers, posters, and radio advertisements have been developed to advertise the toll-free number. Marketing has been targeted to media outlets most popular among key ethnic groups, as well as frequently accessed locations such as supermarkets, churches, schools, modes of public transportation, and area health care provider sites. The primary resources needed are a vendor to provide telephone service and partnerships between community-based organizations across the state and the state health department. Various personnel with the necessary credentials and appropriate training are needed to answer the calls, complete the script and intake forms, make referrals, and follow up on the callers' care. The cost of this program depends heavily on the telephone service used, the number of staff with the required credentials, advertisement of the toll-free number, and any modifications to data systems to provide required reporting.

Benefits

The primary benefit of the proposed toll-free number will be its ability to provide a direct connection between individuals with hemoglobinopathies and comprehensive care. This program also will give those individuals an opportunity to be included in state prevalence estimates, as well as generate high-quality individual-level surveillance data. Pennsylvania anticipates the data will be informative regarding demographics, barriers to care, and the ability to conduct Geographic Information System (GIS) mapping for populations of individuals with hemoglobinopathies to provide effective and continuous care.

Outcomes

The anticipated outcomes are:

- More accurate and reliable information on the number of individuals and families living with SCD and thalassemia.
- Improved knowledge and awareness about SCD and thalassemia.
- Increased access to health care, education, treatment, and supportive services to individuals and families affected by SCD and thalassemia.

By connecting patients with comprehensive care centers, the information obtained by the state will be more reliable for predictions for state resource needs and allocations.

Lessons Learned

Appropriations should be made to anticipate delays in program implementation, such as working with the telephone service provider and coordinating the logistics of connecting each caller with the necessary service and follow-up. A thorough and organized process is needed to facilitate a clear and comprehensive plan for disseminating information about the toll-free line to consumers, making sure all health care providers are on board with the procedures and the technical aspects of the toll-free line are working properly.

Next Steps

An assessment of the first month's activities for the toll-free line will be incorporated into ongoing operations and training. Pennsylvania anticipates initial data and feedback on the toll-free telephone number use in March 2012. The toll-free number has been proposed as an ongoing activity for Pennsylvania's comprehensive hemoglobinopathy programs beyond the life of the RuSH grant. The toll-free number concept was chosen because of the ease of access for individuals participating in surveillance and any future registries, and because it is a model that may be replicable from a statewide to a national effort.

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Words from the Field

"As many think of sickle cell as the forgotten disease, the RuSH Program dispels that notion. Call the toll-free number and be informed."

— Stanley Simpkins,
Executive Director, Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter

"If you have sickle cell disease or thalassemia . . . we're here and WE CARE! Call 1-855-4SICKLE TODAY! Through the creation of this 1-855-4SICKLE line, we are committing ourselves to be a resource for all persons with sickle cell disease and thalassemia. It is our intent to be consistent and effective in connecting persons to the resources that they need. Whether that means answering a question for a person who has been in comprehensive care for some time, or for connecting newly identified persons to comprehensive care for the first time, we're here and we care!"

— Andrea Williams,
Executive Director, Children's Sickle Cell Foundation, Inc.

"Why should surveillance reach out to patients with hemoglobinopathies? Because they may not have access to quality care and may be suffering from disease- related complications."

— Dr. Lakshmanan Krishnamurti,
Director of Sickle Cell Program, Children's Hospital of Pittsburgh

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Children's Healthcare of Atlanta
www.choa.org

Children's Hospital of Philadelphia
www.chop.edu

Children's Hospital of Pittsburgh
www.chp.edu

Children's Sickle Cell Foundation, Inc.
http://cscfkids.org/

Community Health Interventions and Sickle Cell Agency
www.communityhealthinterventions.org

Cooley's Anemia Foundation
www.cooleysanemia.org

Cooley's Anemia Foundation
www.cooleysanemia.org

Georgia Health Policy Center
www.gsu.edu/ghpc

Georgia Health Sciences University
www.georgiahealth.edu/

Grady Health System
www.gradyhealth.org

Memorial Healthcare System: Sickle Cell Day Hospital
www.floridasickle.org

NC Sickle Cell Syndrome Program
http://www.ncsicklecellprogram.org/

New York State Department of Health, Congenital Malformations Registry
http://www.health.ny.gov/diseases/congenital_malformations/cmrhome.htm

New York State Department of Health, Newborn Screening Program
www.wadsworth.org/newborn/index.html

North Carolina Governor's Council on Sickle Cell Disease and Related Disorders

Pennsylvania Oncology Hematology Associates
http://pennoncology.com

Piedmont Health Services and Sickle Cell Agency
www.piedmonthealthservices.org

Shenango Valley Urban League
www.svuleague.org

Sickle Cell Disease Association of America, Inc. Eastern North Carolina Chapter
www.sicklecelleasternnc.org

Sickle Cell Disease Association of America, Inc.
http://www.sicklecelldisease.org

Sickle Cell Disease Association of America, Philadelphia/Delaware Valley Chapter
www.sicklecelldisorder.com

Sickle Cell Disease Association of Florida
http://scdaflorida.com/

Sickle Cell Foundation of Georgia, Inc.
http://www.sicklecellga.org

Sickle Cell Society, Inc. - Pittsburgh
www.sicklecellsocietypgh.org

South Central Pennsylvania Sickle Cell Council
http://scpascc.org/

United Neighborhood Facilities Health Care Corp
http://thejfkcenter.org/UNFHCC

University of South Florida
www.usf.edu

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