Connecticut Department of Public Health

Designing a Comprehensive System Across the Life Span

Connecticut's State Plan to Address Sickle Cell Disease and Trait

Prepared By:

Carey Consulting, LLC
In Collaboration with the Stakeholders Group of the
Connecticut Comprehensive Sickle Cell Disease Consortium

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CONNECTICUT DEPARTMENT OF PUBLIC HEALTH

Keeping Connecticut Healthy

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Acknowledgements

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Appendices

Acknowledgements

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Background Information on the Development of the Plan

In April 2006, the Connecticut Department of Public Health (DPH) retained Carey Consulting to develop a statewide comprehensive plan for addressing the needs of individuals (children and adults) with sickle cell disease (SCD) or trait and supporting their families. Between April and December 2006, the consultant and a student intern from Southern CT State University's Masters of Public Health program met and worked with DPH staff, members of the sickle cell stakeholders group, staff and volunteers at the Southern Regional Sickle Cell Association (SRSCA) and the Citizens for Quality Sickle Cell Care (CQSCC). The planning process was facilitated and guided through three ad hoc workgroups.

Ad Hoc Workgroup	Charge
Implementation/administration CoChairs: R. Thrall & J. Rawlins	To design and implement the Centers of Excellence from an administrative and fiscal perspective
Clinical Chair: Lawrence Solomon	To design and operationalize the Centers' clinical care including pediatric, adult and transitional care and services.
Outreach, public awareness and provider education Chair: Robin Leger	To develop a public awareness campaign and provider education curriculum on sickle cell disease.

See Appendix B for a listing of the meetings that were held during this planning process; Appendix C for a copy of the interview tool utilized with SRSCA and CQSCC.

The plan presented in this report was reviewed and approved at the November 20, 2006 stakeholders' meeting. Since many of the plan's recommendations are already being implemented, this report reflects a work in progress as well as a blueprint for continuing to establish and maintain a comprehensive delivery system across the lifespan for the treatment and care of those with SCD and trait.

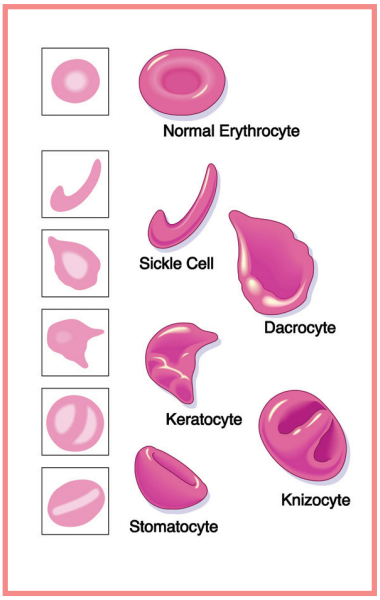
> *"The best way to describe it is like the worst toothache you can imagine. Now take that pain and put it in your back, your legs, your chest. It's constant."*
>
> A patient of the Comprehensive Sickle Cell Center, Montefiore Hospital in New York, 2005

Sickle Cell Trait

Sickle cell trait is different from sickle cell anemia. A person with sickle cell trait does not have the disease but carries the gene that causes the disease. People with sickle cell trait can pass the gene on when they have children. When two people with sickle cell trait have a baby, there is a one in four chance (25 percent) the baby will inherit two sickle cell genes and have the disease; a one in four chance (25 percent) the baby will inherit two normal genes and not have the disease or trait; and a two in four chance (50 percent) the baby will inherit one normal gene and one sickle cell gene. When the last situation occurs the baby will not have the disease but will have sickle cell trait like the parents.

Sickle Cell Disease

Sickle Cell Disease (SCD) is a group of inherited red blood cell disorders. Sickle red blood cells become hard, sticky and shaped like sickles used to cut wheat. When these hard and pointed red cells go through the small blood tube, they clog the flow and break apart. This can cause pain, and a low blood count or anemia.[1]



Sickle cell anemia is common among people whose ancestors come from sub-Saharan Africa, Spanish speaking regions of the world (South America, Cuba, and Central America), Saudi Arabia, India, and Mediterranean countries such as Turkey, Sicily, Greece, and Italy. In the United States, sickle cell anemia occurs in about 1 in every 500 African-American children born and in 1 in every 1,000 -1,400 Hispanic American children born.[2]

Sickle cell disease can lead to a number of complications including:

- **Stroke** - A stroke can occur if sickle cells block blood flow to the brain. It is one of the most serious complications of the disease.
- **Acute chest syndrome** - Acute chest syndrome is similar to pneumonia, but is caused by a lung infection or trapped sickle cells in the lungs. Recurrent attacks can lead to lung damage.
- **Organ damage** – Sickle cells can block blood flow through blood vessels, depriving an organ of blood and oxygen. In sickle cell anemia, blood is also chronically low on oxygen. Chronic deprivation of oxygen-rich blood can damage nerves and organs, including kidneys, liver and the spleen.[3]

In addition to the complications cited above, pain is one of the most common and distressing symptoms that sickle cell patients have.

[1] The Sickle Cell Information Center, The Georgia Comprehensive Sickle Cell Center at Grady Health System, The Sickle Cell Foundation of Georgia, Inc., Emory University School of Medicine Department of Pediatrics, Morehouse School of Medicine, Atlanta, Georgia. Available on online at http://www.scinfo.org/sicklept.htm. Accessed October 2006.

[2] Kugler, M. About Rare Diseases: Sickle Cell Anemia. Inherited Blood Disorder Causes Anemia, Pain. Available on online at http://rarediseases.about.com/od/rarediseasess/a/sicklecell.htm. Accessed October 2006.

[3] Mayo Clinic Medical Services, Mayo Clinic.com, Tools for healthier lives, Sickle Cell Anemia. Available on online at http://www.mayoclinic.com/health/sickle-cell-anemia/DS00324/DSECTION=6. Accessed October 2006.

Sickle Cell Statistics from Connecticut

Since 1964, CT has conducted newborn screenings on all infants born in CT hospitals. The screenings, legislatively mandated and cited in CT General Statutes, Sec. 19a-55, include testing for sickle cell disease and sickle cell trait. Families who have babies born with the disease or with the trait receive a letter from the DPH. In addition, those who have babies with a positive screening test are referred to one of the two comprehensive sickle cell treatment centers located at Yale New Haven Hospital (YNHH) and CT Children's Medical Center (CCMC) located in Hartford. To date, newborn screenings have identified over 374 babies with the disease and 11,930 with the trait.[4]

Connecticut Health Information Management and Exchange (CHIME) is a data collection and analysis service affiliated with the Connecticut Hospital Association (CHA). Currently, the CHIME data collection consists of inpatient admissions, hospital-based ambulatory surgery, and emergency department visits for all thirty (30) of Connecticut's acute care hospitals. CHIME summarizes the data to provide utilization, financial, management, and other types of reports. The state plan is based on the data that were analyzed by the CT Comprehensive Sickle Cell Disease Consortium for the calendar year 2005 and Principal Diagnosis Code or International Classification of Diseases 9th Edition (ICD-9) of 282.6 Sickle Cell Anemia. It should be noted that the data in Appendix D, Table 1 measure total ER utilization. Different individuals may display markedly different ER utilization rates.

CHIME data, as indicated in Appendix D, show the following statistics that have influenced the system design for comprehensive services to those with SCD or trait –

1. In 2005, adults had two times more Emergency Room (ER) visits (1,143 visits) as compared to children (461 visits). See Appendix D, Table 3.
2. Not only are the adults admitted to the hospital at a higher rate than children but they also have longer average lengths of stay (ALOS). The ALOS for children is 6.54 compared to adults at 8.73 days, 34% longer than children. See Appendix D, Table 4.
3. In terms of the different types of payers that provide coverage for SCD patients, the data show that Medicaid paid for 47% of all discharges while Medicare paid for 24%. Private paid party payers (indemnity, managed care) paid a combined 24%. See Appendix D, Table 5 and Chart 5a.
4. In 2005, the charge associated with treating SCD at acute care hospitals in Connecticut was $14.4 million. Of that, $3.8 million was for pediatric treatment (these amounts do not add to the total) while $10.6 million was for adult treatment. Thus, illustrating a disproportional utilization in that ~3 times more charges are associated with adults who comprise only ~ 50% of SCD patients in Connecticut. See Appendix D, Table 6.
5. In contrast to ER admissions, which were more often utilized by adults (71%), children had twice the number of non-emergency room admissions as compared to adults. See Appendix D, Table 7.[5]

Based on the demographics from newborn screening and CHIME data, the majority of individuals with SCD live in the cities of Hartford, New Haven and Bridgeport, making them high priority areas for services to individuals with the disease and their families.[6]

On the national level, the federal Agency for Healthcare Research and Quality (AHRQ) recently released an analysis of sickle cell disease hospitalizations. In 2004 roughly 83,000 hospital stays were for adults and 30,000 were for children. The study found:

- Patients spent about 5 days in the hospital, which cost facilities an average of $6,223 per stay.
- Total hospital costs for sickle cell disease were nearly $500 million in 2004.

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[4] CT Sickle Cell Consortium. Final Report on the Lifespan Approach for Education, Care and Support Services. Sickle Cell Disease Initiative, RFP#BCH 2005-901. Department of Public Health, Bureau of Community Health, Child, Adolescent and School Health Unit. July 2006. Unpublished.

[5] Ibid.

[6] Ibid.

- Medicaid paid for 65 percent of the stays involving patients hospitalized primarily for sickle cell disease, while Medicare paid for 13 percent, private insurers were responsible for 15 percent, and 4 percent of the hospitalized patients were uninsured.[7]

Both nationally and in Connecticut, hospital utilizations and costs are greater for adults than for children. AHRQ's analysis does not differentiate ALOS between adults and children. Their finding of an ALOS of 5 days falls below the ALOS of 6.54 days for children and almost 9 days for adults in CT. In regard to payment of care, Medicaid payments for CT patients (47%) is 18 percent less than the national rate (65%).

The Challenges of the Disease

"We're taught that when patients come in, you make an assessment, you make a diagnosis, and you treat them, and you get results. Sickle cell anemia doesn't always follow that course."

Dr. Lennette Benjamin, Associate Professor of Medicine Albert Einstein College of Medicine, Bronx, NY

For many who have the disease, daily living can consist of illness, pain, unproductive and time-consuming trips to Emergency Departments, stigma and a compromised quality of life. The plan addresses these challenges by responding to the gaps identified by consumers, advocacy organizations, health care providers and others involved in the delivery of services to those with SCD or trait. The planning process benefited greatly from the ongoing work that has been occurring in CT, including the work done by the members of the CT Sickle Cell Consortium in carrying out the DPH's grant – Lifespan Approach for Education, Care and Support Services. The final grant report submitted by the CT Sickle Cell Consortium lists the following gaps, all of which have been recognized and incorporated into the statewide plan -

- more education is needed in the school systems including SC trait counseling
- education to ER physicians and clearly established ER guidelines are needed
- guidelines distinguishing adult and pediatric care must be widely disseminated
- lack of comprehensive transitional care programs
- underutilization of Community and School-Based Health Centers
- underutilization of existing state and federal programs
- confidence level of healthcare provider is not adequate.[8]

CT needs a service delivery system operating across the lifespan that offers consumer involved, family focused and culturally sensitive health care and support services. The Department of Public Health has been working in collaboration with the Comprehensive Sickle Cell Disease (SCD) Consortium. The Consortium consists of the Hospital for Special Care (HSC), as the lead agency; University of Connecticut Health Center (UCHC); Connecticut Children's Medical Center (CCMC); and Citizens for Quality Sickle Cell Care (CQSCC). In 2005, the Consortium received a one year $50,000 Sickle Cell Disease Initiative grant (#2005-901) from DPH. This initiative is known as the "Lifespan Approach for Education, Care and Support Services" and was the vehicle to enhance awareness of SCD among health care providers and to perform a needs assessment of

[7] First Look at Sickle Cell Disease Hospitalizations in 10 Years. AHRQ News and Numbers, December 20, 2006. Agency for Healthcare Research and Quality, Rockville, MD. Available on line at: http://www.ahrq.gov/news/nn/nn122006.htm. Accessed December 2006.

[8] Sickle Cell Consortium. Final Report on the Lifespan Approach for Education, Care and Support Services. Sickle Cell Disease Initiative, RFP#BCH 2005-901.

SCD health care in Connecticut. The Consortium also has a federal three year $183,000 per year grant from Health Resource Services Administration (HRSA) 05-0270 entitled "Connecticut Sickle Cell Newborn Screening Program: Community based Initiative". Funding from this grant began in June 2005 and is designed to enhance the coordinated system of services available for individuals with sickle cell trait. As a result of these initiatives the Consortium has developed statewide partnerships, which include three SCD Community Based Organizations, CQSCC, SRSCA and the CT Chapter of the Sickle Cell Disease Association, DPH and the SCD adult and pediatric services at Yale-New Haven Hospital. Individuals with specialized expertise have joined together to assemble a Steering Committee comprised of a team of "stakeholders" (i.e., consumers, clinicians, families, and investigators) for a comprehensive approach to manage SCD. See Appendix A for a listing of the stakeholders, who also are the guiding force of Connecticut's plan, reflected in this report, to address across the lifespan sickle cell disease and trait. In late fall 2006, the Consortium, via the HSC as the lead agency, was awarded an additional $250,000 one-time grant in response to the DPH's request for proposal (RFP PH1 2007-0911) to establish programs, services and/or partnerships to implement SCD prevention initiatives and interventions for CT residents with SCD or trait. The work that is being done through this grant initiative is supporting much of the work described in the plan. The DPH also secured $14,600 in federal and state funds to retain a consultant to facilitate the planning process and develop this comprehensive state plan, which is built on and reflects the work that has been accomplished.

Review of Best Practices and Strategies For Treating Sickle Cell Disease

Those in Connecticut – advocates, health care providers and consumers of SCD treatment and services – have been informed and guided by a number of initiatives – both in CT and throughout the country – including those identified in the following citations. (See Appendix E for additional resources and organizations relevant to Connecticut's sickle cell disease/trait work.)

- Principles of Care for Children and Adolescents with Sickle Cell Disease

  The principles acknowledge barriers to care that include: being uninsured or underinsured; fear of stigmatization; health care providers who lack an understanding or expertise in treating SCD; families who have had prior bad experiences when seeking care; and cultural and ethnic differences between patient and provider.[9] It should be noted that these barriers to care also apply to adults with SCD.

- Healthy People 2010: Focus Area 16-22 – Increase the Proportion of Children with Special Health Care Needs Who Have Access to a Medical Home

  Healthy People 2010 assigns the following attributes to medical homes if they are to reach their maximum potential –

  - Accessible care, that is care provided in the child's community;
  - Family-centered care, which recognizes the family as the principal caregiver and center of strength and support for children;
  - Continuous care, which assures that the same pediatric health professionals are available from infancy through adolescence and provide assistance with transitions to home, school and adult health services;
  - Comprehensive health care that is available 24/7 and addresses preventive, primary and tertiary needs;
  - Coordinated care, which links families to support, educational and community-based services, and information is centralized;
  - Compassionate caregivers, who express concern for the well-being of the child and family; and

[9] Sickle Cell Disease in Children and Adolescents: Diagnosis, Guidelines for Comprehensive Care, and Care Paths and Protocols for Management of Acute and Chronic Complications. The Sickle Cell Disease Care Consortium (Arizona, Colorado, Georgia, Missouri, New Mexico, Tennessee, Texas, and Utah), Principles of Care for Children and Adolescents with Sickle Cell Disease. Available on online at (http://www.scinfo.org/protchildprinciples.htm). Accessed October 2006.

- Culturally and linguistically appropriate care recognizes values, and respects the family's cultural background[10]
- Acute Illness in Sickle Cell Disease: Illness Requiring Urgent Medical Care

  This write up defines illnesses and emergencies requiring immediate attention and advocates for SC patients to have unimpeded access to those who are best prepared to provide appropriate care. It also provides access to relevant clinical care paths.[11]
- The Comprehensive Sickle Cell Center established by Montefiore Hospital in 1988

  It is only one of 10 sites in the United States that has funding from the National Institutes of Health (NIH). Under the guidance of Drs. Ronald Nagel and Lennette Benjamin, the Center is recognized for its cultural sensitivity and compassionate care to people who live in the Bronx. The Center serves between 300 to 400 people of an estimated 1,400 people with SCD living in the Bronx.[12]
- The Sickle Cell Anemia Day Hospital opened in 1989 by the Montefiore's Comprehensive Sickle Cell Center.

  The Day Hospital was established with the goal of offering alternative care that would improve the timely relief from pain and reduce unnecessary hospital admissions for patients with uncomplicated painful crises. The Day Hospital has successfully reduced the time to achieve relief of pain, increased the number of patients who are discharged home as opposed to being hospitalized, and lessen use of the ED.[13]

[10] U.S Department of Health and Human Services. Healthy People 2010, 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: US. Government Printing Office, November 2000, pages 16, 49 & 50.

[11] Sickle Cell Disease in Children and Adolescents: Diagnosis, Guidelines for Comprehensive Care, and Care Paths and Protocols for Management of Acute and Chronic Complications. The Sickle Cell Disease Care Consortium (Arizona, Colorado, Georgia, Missouri, New Mexico, Tennessee, Texas, and Utah), Principles of Care for Children and Adolescents with Sickle Cell Disease. Available on online at http://www.scinfo.org/protacutecare.htm. Accessed October 2006.

[12] Adamson, L. Sickle Cell Patients Seek Respect. Bronx Beat Online. November 2005. Available on online at http://www.defiers.com/bronx.html. Accessed October 2006.

[12] Benjamin LJ, Swinson GI, Nagel RL. Sickle Cell Anemia Day Hospital: An Approach for the Management of Uncomplicated Painful Crises. Blood. 2000;95: 1130-1136. Available online at: http://www.bloodjournal.org/cgi/content/full/95/4/1130. Accessed October 2006.

The plan has been designed to ensure that those with SC disease or trait are supported, empowered and receive the care that they need to maintain a healthy and productive quality of life despite the constraints of the disease. The plan enhances and expands those resources and services already in place and is consistent with chronic illness care.

Infrastructure Components

One of the challenges confronting members of the workgroups, the stakeholders and consultant was the scope and intensity of the charge. A statewide, culturally sensitive, comprehensive delivery system needs an infrastructure that can capture all aspects of the plan. After several attempts and a final revision of earlier drafts, there was consensus that the following four components capture all the elements needed in a comprehensive delivery system that ensures those with SC disease or trait are supported, empowered and receive the care needed to maintain a healthy and productive quality of life: Outreach & Community–Based Advocacy; Consumer Empowerment/Involvement; Specialty Care via Primary and/or Secondary Care & Tertiary/Inpatient Care; and Education/Research. A definition and budget for each component, as well as for a Statewide Coordination Center, follows.

A Statewide Coordination Center

In order for the infrastructure to function as a seamless delivery system there must be a statewide coordination center responsible for communicating, coordinating and integrating all aspects of the plan as well as tracking, monitoring and evaluating all sickle cell related activities. The annual budget of a fully staffed and operational coordinating center is estimated at $586,950.00. (See next page for a detailed budget.)

"As these things [a statewide comprehensive plan] take time to develop there are still individuals who suffer with the stereotypes and the injustice of being at the mercy of those who lack the knowledge of the disease. It is an almost every day occurrence that I have the opportunity to educate and encourage those to advocate for better care for themselves."

Parent of a child with SCD
September 2006

[7] First Look at Sickle Cell Disease Hospitalizations in 10 Years. AHRQ News and Numbers, December 20, 2006. Agency for Healthcare Research and Quality, Rockville, MD. Available on line at: http://www.ahrq.gov/news/nn/nn122006.htm. Accessed December 2006.

[8] Sickle Cell Consortium. Final Report on the Lifespan Approach for Education, Care and Support Services. Sickle Cell Disease Initiative, RFP#BCH

Statewide Coordination Center Budget

Expenses	Amount	Total Amount	Comment
Salaries:			
Program Director	$ 120,000.00		Position is 100% time
Program Coordinator	$ 65,000.00		Position is 100% time
Dir. of Education & Training	$ 65,000.00		Position is 100% time
Marketing & Development Manager	$ 35,000.00		Position is 50% time
Data Manager	$ 50,000.00		Position is 100% time
Administrative Assistant	$ 40,000.00		Position is 100% time
Total		**$ 375,000.00**	
Fringes (26%)	$ 97,500.00		$375,000 X .26%
Total - Salary and Fringes		**$ 472,500.00**	
Contracted Services			
Project Evaluator	$ 9,450.00		
Media Campaign(s)	$ 30,000.00		Funds should be secured from grants
Hotline & Access to Services Info	$ 20,000.00		
Website - development	$ 20,000.00		This is a one-time cost
Website - maintenance	$ 7,000.00		
Maintenance of hard copy directories	$ 4,000.00		
Total		**$ 90,450.00**	
Operating Expenses			
Rent	In kind		
Supplies - Office	$ 4,000.00		
Supplies - Educational	$ 5,000.00		
Postage	$ 5,000.00		
Phone	In kind		
Printing	$ 5,000.00		
Travel	$ 5,000.00		
Total		**$ 24,000.00**	
	Grand Total	**$ 586,950.00**	

Outreach & Community–Based Advocacy

Outreach includes a multilevel public awareness vehicle to inform the public at large; those at risk for having the disease or trait; and then more targeted information and support for those with the disease or trait. Community-based advocacy refers to increasing awareness, educating and, where appropriate, forming partnerships with other organizations or groups around sickle cell disease or trait. (See Appendix F for a listing of CT state agencies that directly, or by funding direct service programs, work with and/or have resources to support people with SCD/trait. The contact information is provided in order to expedite contacting appropriate individuals for information sharing, networking, and expanding advocacy efforts).

Outreach and community-based advocacy has been and will continue to be carried out by two community-based organizations – The SRSCA and Citizens for Quality Sickle Cell Care (CQSCC). An annual budget for two (2) fully staffed and operational community-based advocacy organizations is $1,475,200. (See next page for a detailed budget.)

Outreach & Community–Based Advocacy Budget

Expenses	Amount	Total Amount	Comment
Salaries:			
Executive Director	$65,000	$130,000	Position is 100% time per CBO
Coordinator of Community Outreach and Advocacy	$60,000	$120,000	Position is 100% time per CBO
Patient Advocate/Systems Navigator	$60,000	$120,000	Position is 100% time per CBO
Social Worker/Case Manager	$65,000	$650,000	*(Up to 10 case managers based on a standard of care of 1 case manager to 34 clients)*
Administrative Assistant	$40,000	$80,000	Position is 100% time per CBO
Total		**$1,100,000**	Fully funded with 10 Case Managers
Fringes (26%)		$286,000	
Total - Salary & Fringes			**$1,386,000**
Operating Expenses			
Rent - *$500/month*	$6,000	$6,000	*SRSCA's rent is an in-kind contribution. $6,000 for CQSCC is based on an estimate.*
Supplies - Office	$4,000	$8,000	
Supplies – Outreach & Public Awareness	$5,000	$10,000	
Supplies – Support Groups	$5,000	$10,000	*Cost for rental, food, travel and stipends for support group leaders.*
Postage	$4,000	$8,000	
Phone	$3,600	$7,200	*Cost based on a monthly bill of $300 for each organization.*
Printing	$4,000	$8,000	
Travel	$6,000	$12,000	
Total - Operating Expenses		**$69,200**	
Other			
Lab fees for blood tests	$0	$0	*Until May 2008, the cost for testing is covered by the federal HRSA "Newborn Screening Program: Community based initiative."*
Scholarships for staff and consumers to attend workshops and conferences	$10,000	$20,000	
Total - Other		**$20,000**	
Grand Total		**$1,475,200**	

Consumer Empowerment/Involvement

Consumer empowerment is the active participation of a person with SCD and/or his/her family in accessing and obtaining needed care in a timely and appropriate manner. Consumer involvement refers to the participation of consumers in the plan-

ning, implementation and evaluation of all aspects of the SCD/trait delivery system. The importance of ongoing, active consumer involvement in the design and delivery of services for those with SCD or trait warrants that it be a discrete component of the infrastructure as well as embedded within the other three components. While consumer involvement has been recognized as essential for ensuring success as measured by the end user, the various ways in which this will be done is evolving within the implementation phase. The advocacy organizations are the major vehicle for bringing consumers into the process and in ensuring that the process is always consumer friendly and family focused. The cost for consumer empowerment/involvement is integrated into the budgets for the Statewide Coordination Center, Outreach & Community–Based Advocacy, and Specialty Care via Primary and/or Secondary Care & Tertiary/Inpatient Care.

Specialty Care via Primary and/or Secondary Care & Tertiary/Inpatient Care

Primary care is the care received by a patient's primary care provider, which can be a doctor, physicians assistant or advanced practice registered nurse. Primary care can be obtained at a number of health care settings, including a private practice, a clinic setting or a community health center. Ideally, primary care should be provided within a medical home model, with the ability to coordinate and integrate all aspects of care. Secondary care, when a patient is referred to and seeing a specialist including, but not limited to, a hematologist, pulmonologist or gastroenterologist, is specialty care. Tertiary care is inpatient care received at a hospital. The provision of specialty care via primary and/or secondary care & tertiary/inpatient care will be done through the two (2) Comprehensive Sickle Cell Treatment Centers of Excellence (Pediatric and Adult Clinical Care). The centers will be located in the southern and northern regions of the state. The cost for two (2) fully staffed and operational Centers of Excellence is $3,751,200. (See budget for detail.)

Specialty Care via Primary and/or Secondary Care & Tertiary/Inpatient Care Budget

Expenses	Amount	Total Amount	Comment
Salaries:			
Adult Hematologist	$200,000	$400,000	Position is 100% time per Center
Pedi Hematologist	$200,000	$400,000	Position is 100% time per Center
Pedi Nurse Practitioner	$80,000	$160,000	Position is 100% time per Center
Adult Nurse Practitioner	$80,000	$160,000	Position is 100% time per Center
Transition Nurse	$80,000	$160,000	Position is 100% time per Center
Pedi Social Worker	$65,000	$130,000	Position is 100% time per Center
Adult Social Worker	$65,000	$130,000	Position is 100% time per Center
Admin Asst.	$40,000	$80,000	Position is 100% time per Center
Case Managers: (5 pediatric)	$325,000	$650,000	*(Up to 5 case managers per Center based on a standard of care of 1 case manager to 34 clients)*
Case Managers: (5 adult)	$325,000	$650,000	*(Up to 5 case managers per Center based on a standard of care of 1 case manager to 34 clients)*
Total		**$2,920,000**	
Fringes (26%)		$759,000	($2,920,000 X 0.26)
Total - Salary & Fringes		**$3,679,200**	
Operating Expenses			
Rent	In kind		
Supplies - Office	$6,000	$12,000	
Educational Materials	$15,000	$30,000	
Phone	In kind		
Travel	$15,000	$30,000	
Total		**$72,000**	
Grand Total		**$3,751,200**	

Education/Research

Research is the scientific investigation of sickle cell disease/trait and education is the vehicle used to share information and keep providers and consumers current on the research. The cost for education/research is integrated into the budgets of the statewide coordination center, outreach & community-based advocacy and specialty care via primary and/or secondary care and tertiary/inpatient care.

The total budget for a fully operational comprehensive state plan to address sickle cell disease/trait is $5,741,350.

Plan Overview and Priority Activities

Building on the statewide Coordination Center and the four infrastructure components, the following chart adds workplan activities. As indicated in the chart, infrastructure components are not mutually exclusive, activities often span more than two or more of the components, especially consumer empowerment/involvement, with is integrated throughout the plan.

The chart also reflects the plan priorities determined by both consumers and providers. For more information on the process used to rate priorities, see Appendix G. Starting on the second page of Appendix G, there are two columns indicating the priority level (high, medium or low) from providers (P) and consumers (C). The levels were determined based on a weighted voting process that was done with the stakeholders at the September 21, 2006 meeting and that consumers submitted by fax and email following the September 21 meeting.

In addition to not being mutually exclusive, work plan activities are not static. In some instances planning and implementation have been occurring in tandem. Implementation efforts reflect the ongoing work being done in the state by health care providers, advocacy organizations and consumers. This work has been supported by state and federal grants, including DPH's funded "Lifespan Approach for Education, Care and Support Services" that ended in June 2006; the HRSA funded "CT Community-Based Initiative: Enhance Sickle Cell Trait Follow-Up Services" that will run until May 2008; and the newly funded grant from DPH that supports ongoing statewide work. The work carried out through the HRSA grant as well as the activities in the new DPH grant (#2007-0294) are reflected in the state plan. (See Appendix G for a copy of the detailed approved state plan, including the ranking of priorities determined by both consumers and providers.)

Summary of CT's Comprehensive Plan to Address Sickle Cell Disease/Trait

Activities	Outreach & Community - Based Advocacy	Consumer Empowerment/ Involvement	Specialty Care Via Primary/ Secondary and/or Tertiary Care	Education/ Research
Create and maintain an infrastructure mechanism to provide communication, coordination and integration among all the infrastructure components and to track, measure and evaluate sickle cell related activities	❍	❍	❍	❍
Do outreach and provide information and testing via schools and colleges; child care programs; faith-based organizations; and community-based organizations	❍	❍		
Offer follow-up services to those who test positive for the disease or trait	❍	❍		
Develop and carry out an ongoing, multi-level media campaign	❍	❍		
Design and carry out a legislative education and advocacy campaign at both the state and federal level.	❍	❍		
Establish and maintain a 24/7 hotline	❍	❍		
Create and maintain a website	❍	❍		
Offer on going support groups where needed in the state	❍	❍		
Keep current hard copy directories (for consumers and providers)	❍	❍		
Develop and formalize partnerships on the state and local levels	❍	❍		
Offer genetic counseling	❍	❍		
Provide newborn screening to identify babies with SCD or trait	❍	❍		
Offer follow-up information and referrals to families with SCD or trait	❍	❍		
Offer screening and follow-up counseling through community based outreach efforts	❍	❍		
Offer respite care to families with children with SCD	❍	❍		
Explore using home visitation resources for patients in need of care that can be provided in the home		❍	❍	
Establish ED protocols for treating patients with SCD and train/support hospitals in implementing them	❍	❍	❍	❍
Establish two (South and North) Centers of Excellence for SCD/trait	❍	❍	❍	❍
Establish advocacy protocols for treating patients with SCD and train patient advocates for implementation at health care facilities	❍	❍	❍	❍
Establish protocols for medical homes that care for patients with SCD and train/support providers in implementing them	❍	❍	❍	❍
Provide, within a context of cultural and ethnic sensitivity, education and training to health care providers, including the continued training that was established through the DPH funded CT Sickle Cell Consortium "Lifespan Approach to Education, Care and Support Services" as well as the Hemoglobinathy training even after the HRSA funding ends in 2008. Offer training and support to staff and community health centers (CHCs), school based health centers (SBHCs) and to school nurse. Explore the feasibility of credentialing SCD providers that can then be replicated on a national level.	❍	❍	❍	❍
Establish protocols for transitioning patients with SCD from pediatric to adult care and train/support provides in implementing the transitional process.	❍	❍	❍	❍
Explore and support the use of Complimentary and Alternate Medicines (CAMs)	❍	❍	❍	❍
Develop and formalize partnerships on the international/ national level.	❍	❍	❍	❍

Priorities

At the November 20, 2006 stakeholders' meeting, the plan and rating of priorities were presented and discussed. The areas that scored the highest by both consumers and providers listed in the chart are:

- Establish ED protocols for treating patients with SCD and train/support hospitals in implementing them.
- Provide education and training to health care providers
- Establish protocols for transitioning patients with SCD from pediatric to adult care and train/support providers in implementing the transitional process.

There was consensus that all three of these areas are moving forward.

- The CT Hospital Association is working on ED protocols and will be sharing them with advocates.
- Education and training of health care providers is offered through the continuation of the HRSA-supported hemoglo binopathy counselor certification training, which will be supplemented with the training offered through the new DPH grant that was awarded to a collaborative of partners – The Hospital for Special Care; the University of CT Health Center, Citizens for Quality Sickle Cell Care and Yale New Haven Hospital's SCD Pediatric Specialized Treatment Center.

This grant award provides the resources needed to establish a Learning Collaborative that will provide SCD content to primary care physicians.

- In regard to the transitioning of patients from pediatric to adult care, the new DPH grant is also supporting a Transition Care Initiative, which will identify patients from the CCMC comprehensive SCD center and create individualized transition care plans for them.

Participants at the meeting also agreed that legislative advocacy, while not rated as a high priority by either consumers or providers, needs to be addressed immediately as the CT legislative session begins the first week in January 2007. There needs to be a consistent legislative agenda that is supported and advocated by all stakeholders and the organizations that they represent. The information needs to be shared, not only with legislators, but also within partner organizations and with consumers and related groups/agencies. Once the legislative agenda is finalized, a brief one-page fact sheet needs to be developed and used consistently by everyone advocating for more awareness of, and support for, addressing SCD/trait.

As the implementation phase continues to move forward, there was a recommendation that the workgroups continue to meet. The workgroups mentioned are clinical (chaired by Larry Solomon); outreach (chaired by Robin Leger) and implementation and administration (chaired by Roger Thrall and Jim Rawlings) with a short term refocus on legislative advocacy.

Short-Term Timeline - 2007 Activities

The following is a listing of activities within a one-year timeframe for operationalizing aspects of the plan. It incorporates the work that has been and will continue to be carried out through the HRSA funded "CT Community-Based Initiative: Enhance Sickle Cell Trait Follow-Up Services" that will run until June 2008; and the newly funded grant (#2007-0294) from the DPH that supports ongoing statewide work. The chart is designed as a tool to monitor progress in accomplishing tasks, to revise, if needed, either activities and/or timeframes, as well as adding or eliminating some tasks as the process moves forward.

(Note 1: An X indicates when a specific task should be accomplished. Arrows (=>) indicate ongoing plan activities. Note 2: **Bolded** activities indicate plan priorities.)

Maintenance of Effort

Activities	QUARTERS 1st	2nd	3rd	4th
Continue stakeholders' meetings.	=>	=>	=>	=>
Continue planning and implementation efforts through the workgroups (outreach, clinical and administrative/legislative advocacy).	=>	=>	=>	=>
Do searches on potential funding sources to ensure sustainability and expansion of services and apply to appropriate sources that are identified.	=>	=>	=>	=>
Maintain hard copy directories (for providers and consumers).				
Review and revise workplan as needed.				X

Maintenance of Effort and Consumer Empowerment/Involvement

Activities	QUARTERS 1st	2nd	3rd	4th
Continue the planning process for two (North and South) Centers of Excellence for SCD.	=>	=>	=>	=>
Continue meetings of all established support groups.	=>	=>	=>	=>
Develop or enhance local community network/partnerships to enhance the quality of life for young adults with SCD and their families by establishing a Project Advisory Counsel (PAC) to advise on, and oversee implementation of goals and objectives of the newly funded DPH project. (#2007-0911)	X	X	=>	=>

Maintenance of Effort, Outreach & Community Based Advocacy and Consumer Empowerment/Involvement

Activities	QUARTERS 1st	2nd	3rd	4th
Continue the Sickle Cell Outreach Peer Education (SCOPE) program in order to expand the recruitment and training of students as peer educators.	=>	=>	=>	=>
Establish a statewide infrastructure to support and maintain support groups. Develop protocols for recruiting, training and retaining support group facilitators; determine where meetings are needed and should be held; and establish the cost of holding groups. Once the information is obtained an annual support group workplan and budget should be developed.		X	X	=>

Outreach & Community Based Advocacy and Consumer Empowerment/Involvement

Activities	QUARTERS 1st	2nd	3rd	4th
Develop a legislative agenda and design fact sheets for legislators that support the agenda.	X			
Share legislative agenda with organizations working with SCD patients, other colleagues, families and legislators (January to June).	=>	=>		
Expand support groups to other communities.			=>	=>
Organize statewide peer support group(s) among young adult SCD patients and/or families (via the new DPH grant - #2007-0911).			X	=>

Outreach & Community Based Advocacy and Consumer Empowerment/Involvement

Activities	QUARTERS 1st	2nd	3rd	4th
Provide, through the SCD Patient Advocate and System Navigator (PASN), consumer assistance and empowerment through advocacy education, healthcare information, and utilization of community based resources to consumers (via the new DPH grant - #2007-0911) Note: For more information on the role and work of the PASN, see the write ups under the Medical and the Outreach, Consumer Empowerment/Involvement and Medical sections listed below.				=>
Explore the establishment of a telephone hot line and a telephone information and referral (I&R) service.				X

Medical Care

Activities	QUARTERS			
	1st	2nd	3rd	4th
Identify two (2) pediatric primary care practices that currently care for SCD patients and establish a medical home network to apply the Learning Collaborative Model (via the new DPH grant - #2007-0911).			X	=>
Hire the Northern (CCMC staff) and Southern (YNNH) regional social workers (via the new DPH grant - #2007-0911)		X		
Hire the transition care coordinator (via the new DPH grant - #2007-0911)			X	

Consumer Empowerment/Involvement and Medical Care

Activities	QUARTERS			
	1st	2nd	3rd	4th
Hire a SCD Patient Advocate and System Navigator (PASN) to integrate health care services (via the new DPH grant #2007-0911).			X	
Create and implement a flexible transition plan template adaptable for individualized services. This task will be done by the transition care coordinator, who is hired as noted under the Medical Care section with DPH funds (via new grant - #2007-0911)			X	=>

Outreach & Community Based Advocacy, Consumer Empowerment/Involvement and Medical Care

Activities	QUARTERS			
	1st	2nd	3rd	4th
Develop/sustain, through the SCD Patient Advocate and System Navigator (PASN), collaborative linkages with consumers, families, providers, and advocacy groups. (Via the new DPH grant - #2007-0911)			X	=>
Provide through the newly hired regional social workers (noted under the Medical Care section) patient advocacy and access to care and support services (via the new DPH grant - #2007-0911)			X	=>
Provide through the newly hired transition care coordinator (noted under the Medical Care section) patient advocacy and access to care and support services (via the new DPH grant - #2007-0911)			=>	=>

Consumer Empowerment/ Involvement, Medical Care and Education/Research and Medical Care

Activities	QUARTERS			
	1st	2nd	3rd	4th
Offer hemoglobinopathy counselor certification trainings (via the HRSA grant)	X		X	
Finalize ED protocols and implement in hospital EDs.	X	X	=>	=>
Develop an SCD-specific Chronic Illness Model of Care Coordination focusing on transition care that interfaces with the pediatric and adult primary care Medical Home concept (via the new DPH grant - #2007-0911) and implement the model.		X	=>	=>
Establish and implement a Learning Collaborative to educate Medical Home and adult primary care providers on the SCD related content consisting of the Chronic Illness Model of Care Coordination, Transition Care Planning, Pain Management, use of Hydroxyurea (via the new DPH grant - #2007-0911).		X	=>	=>

* Medical Care is substituted for Specialty Care via Primary/Secondary and/or Tertiary Care.

Closing Comment

This plan reflects the knowledge, skills, expertise and passion of a dedicated group of action-oriented individuals. With financial support from the DPH and HRSA, many aspects of this plan are already being implemented. Hopefully, the work done through the planning process provides a frame of reference for staying on target and, when necessary, revising tasks and goals. As Connecticut's SCD initiatives move forward the state is well poised to serve as a model in delivering services and support to those with SCD or trait and/or their families.

Appendix A
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July 2006

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Appendix A (cont.)
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Appendix B
List of Meetings Held During the Planning Process

April 10	Meeting with Roger Thrall, Hospital of Special Care, lead person on DPH and HRSA funded grants
April 21	Meeting with Vine Samuels and Lisa Davis, DPH staff (Friday)
April 27	Meeting with Roger Thrall
May 8	Meeting with Peter Ennin, Southern CT State University Masters in Public Health student intern
May 11	Meeting with Beverly Burke and Mary Pettigrew, DPH staff
May 19	Planning meeting with Roger Thrall, Mary Pettigrew, Lisa Davis, Vine Samuels, and Peter Ennin
June 12	Meeting with Roger Thrall
June 15	Meeting with Roger Thrall & Jody Blumberg, Research Outcomes Specialist for Hospital for Special Care
June 27	Meeting with Robin Leger, UCONN Health Center, Chair of the Outreach & Public Awareness Workgroup
July 7	Interview with Marcia Smith Glasper, President of the Citizens for Quality Sickle Cell Care (CQSCC)
July 11	Interview with Delores Edwards, Executive Director of the South Regional Sickle Cell Association (SRSCA)
July 18	Meeting with Roger Thrall
July 20	Outreach & Public Awareness Workgroup meeting
July 20	Stakeholder's meeting
August 2	Meeting with Vine Samuels and Lisa Davis
August 16	Outreach & Public Awareness Workgroup meeting
August 17	Administration and Implementation Workgroup meeting
August 30	Clinical workgroup meeting
Sept. 5	Conference call with Roger Thrall
Sept. 21	Stakeholder's Meeting, presented overview of the CT State Plan Infrastructure
Oct. 17	Meeting with Vine Samuels and Lisa Davis
Oct. 31	Meeting with Delores Edwards
Nov. 6	Meeting with Dick Edmonds and Lisa Davis
Nov. 20	Stakeholders' meeting, presented plan for review and approval

Appendix C
Connecticut Sickle Cell Disease – Advocacy Organization Survey
June 2006

This survey is collecting information about your organization and the individuals and families you serve. Your response will help the Department of Public Health establish a comprehensive state plan on sickle cell disease. This survey is funded by the CT Department of Public Health.

Name of organization: _____

Person interviewed & title: _____

Background information on person being interviewed, including, but not limited to, years involved with the organization, job function and specific responsibilities.

_____

_____

1. What is the mission of your organization?

_____

_____

_____

2. Are you associated with the national Sickle Cell Disease organization?

___ yes ___ no

2a. If yes, are you in good standing with the national organization?

___ yes ___ no

2b. What are the benefits of belonging to a national organization?

3. Is your organization a member of any other national or regional organization(s)?

___ yes ___ no

3a. If yes, what are the organizations?

_____

_____

4. Are you a private non-profit organization?

___ yes ___ no

4a. If yes, are you registered with the Secretary of State?

___ yes ___ no

4b. If no, how would you classify your organization?

5. How long has your organization been in operation?

___ less than a year
___ between a year and three years
___ between four and six years
___ between seven and ten years
___ more than 10 years.

6. How many people serve on your Board of Directors? Can we have a list of Board members?

___

7. Do you have an organizational chart? If yes, can we have a copy?

___ yes ___ no

8. Do you have a current annual report? If yes, can we have a copy?

___ yes ___ no

9. List and describe your organization's staff and volunteers positions.

Staff position 1

Job Title: _____

Number of FTEs: ___ Any vacancies? ___ yes ___ no

Job description: _____

Does position required licensure? ___ yes ___ no

If yes, what type of licensure does the staff person have?

_____

Staff position 2

Job Title: _____

Number of FTEs: ___ Any vacancies? ___ yes ___ no

Job description: _____

Does position required licensure? ___ yes ___ no

If yes, what type of licensure does the staff person have?

_____

Staff position 3

Job Title: _____

Number of FTEs: ___ Any vacancies? ___ yes ___ no

Job description: _____

Does position required licensure? ___ yes ___ no

If yes, what type of licensure does the staff person have?

_____

Staff position 4

Job Title: _____

Number of FTEs: ___ Any vacancies? ___ yes ___ no

Job description: _____

Does position required licensure? ___ yes ___ no

If yes, what type of licensure does the staff person have?

_____

Staff position 5

Job Title: _____

Number of FTEs: ___ Any vacancies? ___ yes ___ no

Job description: _____

Does position required licensure? ___ yes ___ no

If yes, what type of licensure does the staff person have?

_____

Volunteer position 1

Volunteer Job Title: _____

Number of volunteers in this position?: ___

Description of tasks: _____

Does position required licensure? ___ yes ___ no

If yes, what type of licensure does the staff person have?

_____

Volunteer position 2

Volunteer Job Title: _____

Number of volunteers in this position?: ___

Description of tasks: _____

Does position required licensure? ___ yes ___ no

If yes, what type of licensure does the staff person have?

_____

Volunteer position 3

Volunteer Job Title: _____

Number of volunteers in this position?: ___

Description of tasks: _____

Does position required licensure? ___ yes ___ no

If yes, what type of licensure does the staff person have?

_____

Volunteer position 4

Volunteer Job Title: _____

Number of volunteers in this position?: ___

Description of tasks: _____

Does position required licensure? ___ yes ___ no

If yes, what type of licensure does the staff person have?

_____

Volunteer position 5

Volunteer Job Title: _____

Number of volunteers in this position?: ___

Description of tasks: _____

Does position required licensure? ___ yes ___ no

If yes, what type of licensure does the staff person have?

_____

10. How are you funded or obtain in-kind support/resources? Check all that apply.

___ federal funding
___ state funding
___ national association
___ foundation/corporate grants
___ membership dues
___ fundraising events
___ Other: describe _____

11. Describe the population that you serve, including geographic area, age range and race/ethnicity.

_____

_____

_____

12. How do those who can benefit from your service find you? Do you have any brochures or other marketing materials? If yes, can we have a copy? Do you have a website? If yes, what is the address?

_____

_____

13. What is the average number of people you serve on a monthly or annual basis?

_____

_____

14. Where do most of your clients receive their ongoing health care?

___ private practice health care provider
___ hospital clinic
___ community health center
___ emergency department
___ Other: describe _____

15. What percentage of your clients do you estimate have the following health insurance coverage?

___ Private insurance
___ Medicaid (HUSKY A)
___ Medicaid (fee for service)
___ HUSKY B (State Child Health Insurance Program)
___ SAGA (State Administered General Assistance)
___ Other: describe _____
___ No coverage
___ Don't know

Connecticut Sickle Cell Disease – Advocacy Organization Survey

16. What services do you offer or refer to? For each service, check off if the service is provided directly or if you refer out for services.

Service	Provide	Refer to	N/A	Comment
Advocacy - client level				
Advocacy - systems level				
Case management				
Counseling				
Crisis hotline				
Education				
Employment assistance				
Financial support for medical expenses				
Financial support for living expenses				
Genetic counseling (pre-birth)				
Help with English language or				
Housing assistance				
Legal services				
Nutrition supplement				
Parent support groups/classes				
Respite care				
Sickle cell support groups				
Social work				
Special camps or other recreational				
Transition services from pediatrics to adult care				
Transportation services				
Other: describe				

17. Do you have a working relationship with the following community based organizations/groups?

Service	Yes	No	N/A	Don't know	Comment
Private practice health care providers					
Community health centers					
Hospital clinic and/or ED					
School Based Health Centers					
Religious/spiritual groups					
Municipal services					
Housing Authorities					
Local Health Departments					
211 Infoline					
Legal Aid agencies					
Dental programs					
Child & Family Counseling agencies					
Mental health programs					

17.(Continued)

Service	Yes	No	N/A	Don't know	Comment
Regional DSS office					
Substance abuse treatment programs					
Child care programs					
Schools					
Emergency housing programs					
Emergency food programs					
Other: describe					

18. Do you know about and work with the following state administered programs?

State administered programs	Know	Work with	N/A	Don't know	Comment
Children and Youth with Special Health Care Needs (CYSHCNs)					
WIC					
HUSKY A (Medicaid)					
HUSKY B					
CT Behavioral Health Partnership					
The Birth to Three System					
Food stamps					
TFA (Temporary Family Assistance)					
Other: describe					

19.What is your relationship with the other SC Disease advocacy organizations? How do you work with them?

20. Are you at capacity?

___ yes ___ no

20a. If yes, what are your plans for expanding your services?

21. Are there other services that you would like to offer?

___ yes ___ no

21a. If yes, what are they?

21b. Do you have a plan to provide these services? How much more funding would be needed?

22. On a scale of 1 to 5 with 5 being the highest, how would you rate the services and care available to people with sickle cell disease in CT?

	5	4	3	2	1	Don't know
Medical care for children						
Medical care for adults						
Support services for children						
Support services for adults						
Transitional services						
Other: describe						

22a Describe what you see as the positives.

22b. What do you see as the gaps in serving people with sickle cell disease?

23. What do you feel can be done to improve the delivery of needed care and services?

24. Is there an appropriate role for your organization in addressing the gaps and improving services?

___ yes ___ no

24a. If yes, describe.

25. Is there anything that you would like to share that was not addressed in the questions asked?

Name of person conducting the interview:

Table 1: 2005 Emergency Room (ER) Utilization for SCD of all Ages by Hospital

Hospital	ER Visit leading to Hospital Admission	ER Visit Non Hospital Admission	ER Visit Total
Bridgeport Hospital	49	52	101
Connecticut Children's Medical Center	77	44	12
Danbury Hospital	14	11	25
Day Kimball Hospital	5	2	7
Greenwich Hospital	3	4	7
Griffin Hospital	3	4	7
Hartford Hospital	24	19	43
Hospital of Central CT at Bradley Memorial	1	6	7
Hospital of Central CT at New Britain General	4	3	7
Hospital of Saint Raphael	18	13	31
John Dempsey Hospital	24	19	43
Lawrence & Memorial Hospital	17	35	52
Manchester Memorial Hospital	1	0	1
Middlesex Hospital	11	36	47
Midstate Medical Center	7	5	12
Milford Hospital	0	1	1
Norwalk Hospital	31	64	95
Rockville Hospital	0	1	1
Saint Francis Hospital	46	64	110
Saint Mary's Hospital	35	40	75
St. Vincent's Medical Centers	16	23	39
Stamford Hospital	48	91	139
Waterbury Hospital	11	15	26
William W. Backus Hospital	6	26	32
Yale New Haven Hospital	359	216	575
Total	**810**	**794**	**1604**

Table 2: 2005 Emergency Room (ER) Visits for SCD for All Ages by Metropolitan Area

City	Total
New Haven (Yale and St. Raphael)	606
Hartford (CCMC and Hartford, St Francis, John Dempsey)	317
Bridgeport (Bridgeport, St. St. Vincent's)	240
Stamford	139
Waterbury	101
Norwalk	95

Table 3: 2005 Emergency Room (ER) Utilization for SCD by Age

Hospital	ER Visit leading to Hospital Admission		ER Visit Non Hospital - Admission	
	≤ 18 Years	≥ 19 Years	≤ 18 Years	≥ 19 Years
Bridgeport Hospital	21	28	15	37
Connecticut Children's Medical Center	75	2	44	0
Danbury Hospital	1	13	3	8
Day Kimball Hospital	0	5	0	2
Greenwich Hospital	0	3	0	4
Griffin Hospital	0	3	0	4
Hartford Hospital	0	24	0	19
Hospital of Central CT at Bradley Memorial	0	1	0	6
Hospital of Central CT at New Britain General	0	4	0	3
Hospital of Saint Raphael	0	18	1	12
John Dempsey Hospital	0	24	0	19
Lawrence & Memorial Hospital	5	12	14	21
Manchester Memorial Hospital	0	1	0	0
Middlesex Hospital	0	11	7	29
Midstate Medical Center	0	7	4	1
Milford Hospital	0	0	0	1
Norwalk Hospital	5	26	8	56
Rockville Hospital	0	0	0	1
Saint Francis Hospital	5	41	4	60
Saint Mary's Hospital	22	13	20	20
St. Vincent's Medical Centers	0	16	5	18
Stamford Hospital	5	43	28	63
Waterbury Hospital	5	6	0	15
William W. Backus Hospital	0	6	2	24
Yale New Haven Hospital	119	240	43	173
Total	**263** (32%)	**547** (68%)	**198** (25%)	**596** (75%)

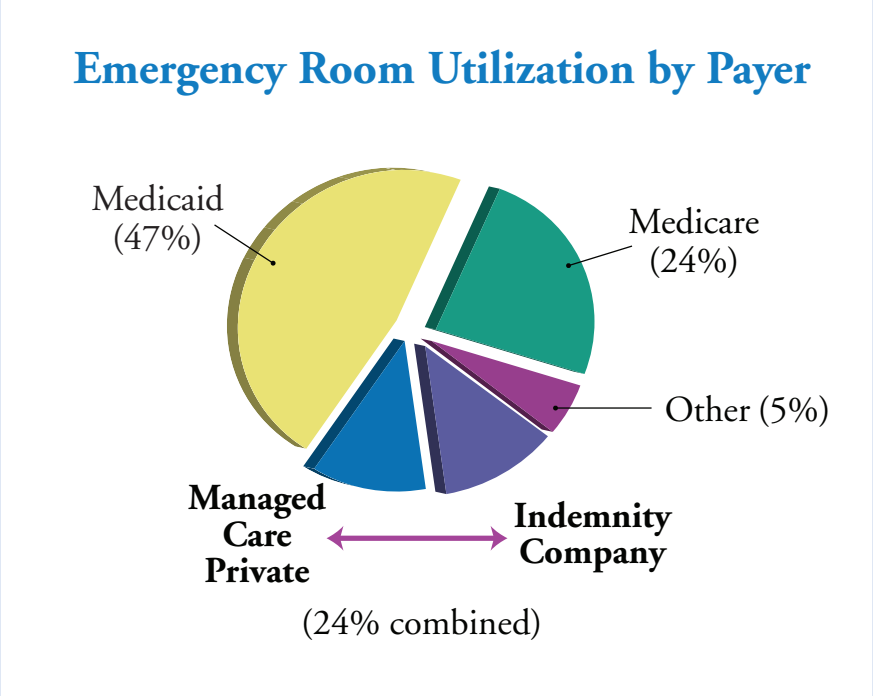
Table 4: 2005 Utilization for SCD by Average Length of Stay (ALOS) and Age

Hospital	Average LOS ≤ 18 Years	Average LOS ≥ 19 Years
Bridgeport Hospital	6.03	4.26
Connecticut Children's Medical Center	5.18	3.60
Danbury Hospital	1.00	4.20
Day Kimball Hospital	0.00	2.29
Greenwich Hospital	0.00	2.43
Griffin Hospital	0.00	1.14
Hartford Hospital	1.00	6.84
Hospital of Central CT at Bradley Memorial	0.00	1.00
Hospital of Central CT at New Britain General	0.00	3.70
Hospital of Saint Raphael	1.00	12.58
John Dempsey Hospital	0.00	8.41
Lawrence & Memorial Hospital	4.10	3.29
Manchester Memorial Hospital	0.00	4.00
Middlesex Hospital	2.17	3.91
Midstate Medical Center	1.00	2.00
Milford Hospital	0.00	1.00
Norwalk Hospital	3.52	1.73
Rockville Hospital	0.00	1.00
Saint Francis Hospital	8.33	8.13
Saint Mary's Hospital	2.62	4.71
St. Vincent's Medical Centers	2.00	4.52
Stamford Hospital	2.63	11.21
Waterbury Hospital	6.58	5.30
William W. Backus Hospital	1.00	2.62
Yale New Haven Hospital	6.54	8.73

Table 5: 2005 Emergency Room (ER) Utilization for SCD by Payer

Hospital	Indemnity Company	Managed Care Private	Medicaid	Medicare	Other
Bridgeport Hospital	9	6	76	11	2
Connecticut Children's Medical Center	15	83	133	0	1
Danbury Hospital	5	0	15	0	5
Day Kimball Hospital	0	0	6	1	0
Greenwich Hospital	3	0	0	0	4
Griffin Hospital	0	0	4	1	2
Hartford Hospital	4	3	21	20	3
Hospital of Central CT at Bradley Memorial	0	0	7	0	0
Hospital of Central CT at New Britain General	2	2	3	0	0
Hospital of Saint Raphael	7	0	7	16	2
John Dempsey Hospital	1	8	23	15	16
Lawrence & Memorial Hospital	4	0	19	31	1
Manchester Memorial Hospital	0	0	0	0	1
Middlesex Hospital	24	11	9	4	1
Midstate Medical Center	1	0	9	1	2
Milford Hospital	0	0	0	1	0
Norwalk Hospital	0	16	27	57	2
Rockville Hospital	0	1	0	0	0
Saint Francis Hospital	38	20	55	14	10
Saint Mary's Hospital	17	1	58	8	4
St. Vincent's Medical Centers	17	9	7	5	2
Stamford Hospital	34	9	13	70	15
Waterbury Hospital	0	3	20	1	5
William W. Backus Hospital	2	1	25	3	1
Yale New Haven Hospital	29	42	326	174	18
Total	**212** (12%)	**215** (12%)	**863** (47%)	**433** (24%)	**97** (5%)

Chart 5a: 2005 Emergency room (ER) Utilization for SCD by Payer



Connecticut Health Information Management and Exchange (CHIME) Data Reports

In 2005, the charge associated with treating SCD at acute care hospital in Connecticut were $14.5 million (Table 6). Of that, $3.8 million was for pediatric treatment while $10.6 million was for adult treatment. Thus, illustrating a disproportional utilization in that ~3 times more charges are associated with adults who comprise only ~ 50% of SCD patients in Connecticut.

Table 6: 2005 Acute Care Hospitals Charges for SCD by Age

Hospital	Total Charges ≤ 18 Years	≥ 19 Years	Total
Bridgeport Hospital	$241,413	$659,593	$901,006
Connecticut Children's Medical Center	$1,318,864	$42,848	$1,361,712
Danbury Hospital	$6,504	$169,342	$175,846
Day Kimball Hospital	$0	$38,637	$38,637
Greenwich Hospital	$0	$61,078	$61,078
Griffin Hospital	$0	$20,140	$20,140
Hartford Hospital	$5,434	$432,265	$437,699
Hospital of Central CT at Bradley Memorial	$0	$20,648	$20,648
Hospital of Central CT at New Britain General	$0	$48,584	$48,584
Hospital of Saint Raphael	$1,701	$349,098	$350,799
John Dempsey Hospital	$0	$1,005,048	$1,005,048
Lawrence & Memorial Hospital	$71,077	$127,325	$198,402
Manchester Memorial Hospital	$0	$10,970	$10,970
Middlesex Hospital	$13,796	$161,730	$175,526
Midstate Medical Center	$3,885	$46,803	$50,688
Milford Hospital	$0	$1,980	$1,980
Norwalk Hospital	$66,176	$352,077	$418,253
Rockville Hospital	$0	$3,265	$3,265
Saint Francis Hospital	$89,621	$1,049,817	$1,139,437
Saint Mary's Hospital	$141,758	$192,984	$334,742
St. Vincent's Medical Centers	$4,100	$128,424	$132,524
Stamford Hospital	$135,038	$880,647	$1,015,685
Waterbury Hospital	$68,969	$165,232	$234,201
William W. Backus Hospital	$3,992	$111,758	$115,750
Yale New Haven Hospital	$1,666,570	$4,589,281	$6,255,850
Total	**$3,838,897**	**$10,669,576**	**$14,508,473**

In contrast to ER admissions, which were more often utilized by adults (71%), children had twice the number of non-emergency room admissions as compared to adults (Table 17).

Table 7: 2005 Non-Emergency Room (ER) Utilization for SCD by Age

Hospital	Non - ER Admission	
	≤ 18 Years	≥ 19 Years
Bridgeport Hospital	3	0
Connecticut Children's Medical Center	108	3
Danbury Hospital	0	0
Day Kimball Hospital	0	0
Greenwich Hospital	0	0
Griffin Hospital	0	0
Hartford Hospital	1	7
Hospital of Central CT at Bradley Memorial	0	0
Hospital of Central CT at New Britain General	0	0
Hospital of Saint Raphael	0	1
John Dempsey Hospital	0	20
Lawrence & Memorial Hospital	1	2
Manchester Memorial Hospital	0	0
Middlesex Hospital	1	1
Midstate Medical Center	0	1
Milford Hospital	0	0
Norwalk Hospital	5	2
Rockville Hospital	0	0
Saint Francis Hospital	0	27
Saint Mary's Hospital	12	1
St. Vincent's Medical Centers	0	1
Stamford Hospital	1	1
Waterbury Hospital	2	1
William W. Backus Hospital	0	0
Yale New Haven Hospital	10	4
Total	**144 (67%)**	**72 (33%)**

Appendix E
Listing of National and CT Based Organizations and Resources

Organization/Resource	Website/Home Page	Brief Description
Citizens for Quality Sickle Cell Care (CQSCC)	http://cqscc.org/evenflyers/fundraiser_4.pdf	CQSCC's website
Southern Regional Sickle Cell Association, Inc (SRSCA)	http://sicklecell.tripod.com/	SRSCA's website
The Sickle Cell Disease Association of America	http://www.sicklecelldisease.org/	The National Sickle Cell Disease Association website
The Sickle Cell Information Center	http://www.scinfo.org/	The site provides patient and professional education, research updates, and other resources.
Information Center for Sickle Cell and Thalassemic Disorders	http://sickle.bwh.harvard.edu/	The information at this site is a free service to the biomedical community. The goal is to provide a source of current information on sickle cell disease, thalassemia, and disorders of iron metabolism. The site includes overviews of basic and clinical research, management, and new developments in the fields.
The Sickle Cell Society	http://www.sicklecellsociety.org/	The Sickle Cell Society believes that every sickle cell sufferer has the right to quality care. This can only be achieved if funding is made available to educate health carers and other professionals about the condition. The Society aims to provide this.
Action Medical Alert: Sickle Cell Disease	http://www.action.org.uk/news_media/sickle_cell.php	Action Medical Research is the UK's most forward thinking charity and believes diseases and disabilities can be beaten, and through medical research we are creating a healthier future for everyone.
Mayo Clinic: Sickle Cell Anemia	http://www.mayoclinic.com/health/sickle-cell-anemia/DS00324	The Mayo Clinic's website for medical information and tools for healthy living
National Pain Foundation	http://www.nationalpainfoundation.org/	An on-line educational and support community for persons in pain, their families and physicians. Your source for treatment options and pain information that is peer reviewed by leading pain specialists.
Teens Health: Sickle Cell Anemia	http://kidshealth.org/teen/diseases_conditions/genetic/sickle_cell_anemia.html	KidsHealth is a project of Nemours, which was established in 1936 by philanthropist Alfred DuPont, and is dedicated to improving the health and spirit of children.
Sickle Cell Disease Association of Dallas	http://www.sicklecelldallas.org/	The Sickle Cell Disease Association of Dallas has four major components - Testing & Screening, Case Management, Genetic Counseling and Public Outreach and Education. The Association supports the sickle cell community through Support Groups, Stress & Pain Management Seminars, Community Service Referrals, Sickle Cell Educational & Achievement Tutorial and Blood Drives.

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Listing of National and CT Based Organizations and Resources

St. Jude Children's Research Hospital	http://www.stjude.org/phecom/0,2777,632_3503_5147,00.html	St. Jude's website on sickle cell disease
International Association of Sickle Cell Nurses and Physician Assistants (IASCNAPA)	http://iascnapa.org/	International Association of Sickle Cell Nurses and Physician Assistants (IASCNAPA) is the only association of nurses, physician assistants, social workers, and other health care professionals caring for individuals with sickle cell disease.
National Coalition for Health Professional Educational	http://www.nchpeg.org/	Established in 1996 by the American Medical Association, the American Nurses Association, and the National Human Genome Research Institute, the National Coalition for Health Professional Education in Genetics (NCHPEG) is an "organization of organizations" committed to a national effort to promote health professional education and access to in formation about advances in human genetics.
The International Society of Nurses in Genetics (ISONG)	http://www.isong.org/	ISONG, the International Society of Nurses in Genetics, is a global nursing specialty organization dedicated to fostering the scientific and professional growth of nurses in human genetics and genomics worldwide.
Genetic Home Reference (Search Sickle Cell)	http://ghr.nlm.nih.gov/	Genetics Home Reference provides consumer-friendly information about the effects of genetic variations on human health.
The Sickle Cell Adult Provider Network (SCAPN)	http://iascnapa.org/who_we_are.htm	International Association of Sickle Cell Nurses The Sickle Cell Adult Provider Network (SCAPN) was established in 2002 in response to the need for communication and support amongst those who provide health care to adults with sickle cell disease. As sickle cell patients live longer, relatively healthier lives, there are a growing number of adults who require expert care from knowledgeable providers. Management of this complex disease can be very challenging, frustrating, discouraging, and very rewarding. A small but significant number of providers have developed considerable expertise in the management of adult sickle cell disease. Our hope is that the SCAPN can serve to facilitate the dissemination of this knowledge and experience in support of the broader community of providers, serve to enhance collaboration in research efforts across traditional boundaries of professions and specialties, and foster the development and expand the number of professional working with adults with sickle cell disease.

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Listing of National and CT Based Organizations and Resources

Northwest Sickle Cell Collaborative	http://www.nwsicklecell.org/	The Northwest Sickle Cell Collaborative (NWSCC) makes life better for children and families with sickle cell disease and sickle cell trait by encouraging, educating and empowering them to take control of their health and improve their quality of life. By partnering with local health care providers, the state's newborn screening program, families, schools and communities, NWSCC ensures that all those affected by sickle cell have access to education, resources, counseling and coordinated care.
The Sickle Cell Disease Foundation of California (SCDFC)	http://www.scdfc.org/	The Sickle Cell Disease Foundation of California was the first non-profit, social service sickle cell disease organization established in the United States. With a growing population of individuals with sickle cell disease and sickle cell trait, the primary focus of the SCDFC is to educate, screen and counsel those persons at risk of having children with sickle cell disease and other hemoglobin disorders.

Appendix F
Listing Of Connecticut State Agencies With Contact Information

Agency	Contact Person	Contact Information
DPH		
Newborn Genetic Screening	Vine M. Samuels	(860) 509-8651 vine.samuels@ct.gov
Children & Youth with Special Health Care Needs (CYSHCNs)	Robin Tousey Ayers Ann Gionet	860-509-8074 - robin.tousey-ayers@ct.gov 860-509-8074 - ann.gionet@ct.gov
Office of Multicultural Health & Comprehensive Cancer	Nancy Berger Michele Stewart Copes	860-509-7804 nancy.berger@ct.gov 860-509-7804 michele.stewart-copes@ct.gov
DMR		
The CT Birth to Three system	Linda Goodman	860-418-6147 linda.f.goodman@ct.gov
DSS		
Medicaid/HUSKY	Tim Bowles Rose Ciarcia	860-424-5390 timothy.bowles@ct.gov 860-424-5139 rose.ciarcia@po.state.ct.us
SAGA (State Administered General Assistance)		
TANF	Kevin Loveland	860 424-5031 kevin.loveland@po.state.ct.us
CT Behavioral Health Partnership	Mark Schaefer	860 424-5067 mark.schaefer@po.state.ct.us
DMHAS		
The Transformation Initiative	Barbara Bugella	860 418-6738 barbara.bugella@ct.gov
Statewide services	Barbara Geller	860-418-6813 barbara.geller@ct.gov
DCF	Karen Snyder	860-550-6633 karen.snyder@ct.gov
SDE	Cheryl Resha	860 807-2108 cheryl.resha@ct.gov
DOC	Mary Marcial	860 692-7494 mary.marcial@ct.gov
The Commission on Children	Liz Brown	860 240-0290 elizabeth.brown@cga.ct.gov
The Permanent Commission on the Status of Women	Theresa Younger Nastasha Pierre	860-240-8300 theresa.younger@cga.gov 860-240-8300 natasha.pierre@cga.ct.gov
Office of the Health Care Access	Vicky Veltri	860 297-3982 victoria.veltri@ct.gov
African American Affairs Commission	Cheryl Forbes	860 240-8555 cheryl.h.forbes@cga.ct.gov

Appendix G
CT's Comprehensive Plan to Address Sickle Cell Disease/Trait

The intent of CT's comprehensive plan to address SCD/trait is to inform the planning process through consumer involvement in creating a statewide, culturally sensitive, comprehensive system that ensures those with SC disease or trait are supported, empowered and receive the care that they need to maintain a healthy and productive quality of life despite the constraints of the disease. The plan enhances and expands those resources and services already in place and is consistent with chronic illness care.

In this chart, plan tasks/activities are presented within the role of a Statewide Coordination Center, with an estimated annual budget of $586,950, and within two or more of the four infrastructure components that were approved by the stakeholders' with an acknowledgement that, collectively, they capture all aspects of the plan. The four infrastructure components are:

• Outreach & Community Based Advocacy

Outreach includes a multilevel public awareness vehicle to inform the public at large; those at risk for having the disease or trait; and then more targeted information and support for those with the disease or trait. Community-based advocacy refers to increasing awareness, educating and, where appropriate, forming partnerships with other organizations or groups around sickle cell disease or trait. Outreach and community-based advocacy has been and will continue to be carried out by two community-based organizations - The South Regional Sickle Cell Association (SRSCA) and Citizens for Quality Sickle Cell Care (CQSCC). An annual budget for two (2) fully staffed and operational community-based advocacy organizations is $1,475,200.

• Consumer Empowerment/Involvement

Consumer empowerment is the active participation of a person with SCD and/or his/her family in accessing and obtaining needed care in a timely and appropriate manner. Consumer involvement refers to the participation of consumers in the planning, implementation and evaluation of all aspects of the SCD/trait delivery system. The cost for consumer empowerment/involvement is integrated into the budgets of the Statewide Coordination Center; Outreach & Community–Based Advocacy; and Specialty Care via Primary and/or Secondary Care & Tertiary/Inpatient Care.

• Specialty Care via Primary/Secondary and/or Tertiary Care

Primary care is the care received by a patient's primary care provider, which can be a doctor, PA or an APRN at a number of health care settings, including a private practice, a clinic setting or a community health center. Secondary care, when a patient is referred to and seeing a specialist including, but not limited to, a hematologist, pulmonologist or gastroenterologist, is specialty care. Tertiary care is inpatient care received at a hospital. The provision of Specialty Care via Primary and/or Secondary Care & Tertiary/Inpatient Care will be done through the two (2) Comprehensive Sickle Cell Treatment Centers of Excellence (Pediatric and Adult Clinical Care). The cost for two (2) fully staffed and operational Centers of Excellence is $3,751,200.

• Education/Research

Research is the scientific investigation of sickle cell disease/trait and education is a vehicle used to share information and keep providers and consumers current on the research. The cost for Education/Research is integrated into the budgets of the Statewide Coordination Center; Outreach & Community–Based Advocacy; and Specialty Care via Primary and/or Secondary Care & Tertiary/Inpatient Care.

Appendix G
CT's Comprehensive Plan to Address Sickle Cell Disease/Trait

All Plan Conponents

Consultant Recommendation - Establish A Statewide Coordination Center

Create and maintain an infrastructure mechanism to provide communication, coordination and integration among all the infrastructure components and to track, measure and evaluate sickle cell related activities. Management responsibilities include but, are not limited to,

- Organize, hold and follow-up on all plan implementation meetings;
- Maintain timely communication among all entities involved in implementing the plan;
- Manage contracts for work/support that might be needed to assist in plan implementation;
- Develop and maintain partnerships with state agencies and their funded programs that have an impact on individuals with sickle cell disease and their families; (See attached listing of state agencies/programs)
- Take the lead on legislative education and advocacy efforts (state and federal level) and identify partners with common issues in order to maximize input;
- Research potential funding sources, share with others and help with determining how and by whom funding opportunities should be sought;
- Develop and maintain data collection systems to track, monitor and measure SC related activities; and
- Explore options for a 24/7 hotline, an information and referral service, a website and printed directories.

Comment/Cost Estimate

An estimated annual budget for a Statewide Coordination Center is $586,950.

Outreach & Community Based Advocacy And Consumer Empowerment/Involvement

Priority Level		
P	**C**	**Recommendation**
Med	Med	Conduct outreach/info and testing via schools (high schools and colleges), faith based organizations and community based organizations.

Implementation Options

Use the SCOPE program to expand the recruitment and training of students as peer educators and continue to educate individuals and the community about SCD/trait.

Begin the mobilization of community resources as described in the new DPH grant.

Comment/Cost Estimate

An ongoing quarterly workplan, incorporating the options listed above needs to be developed collaboratively by all those involved in delivering the services. The workplan will help to coordinate efforts by identifying the who, what, where and when these activities will occur. A data collection system also needs to be established to track and measure outreach efforts.

The cost for expanding current outreach and education activities is integrated into the Statewide Coordination Center and the two advocacy organizations' budgets.

Appendix G
CT's Comprehensive Plan to Address Sickle Cell Disease/Trait

Outreach & Community Based Advocacy And Consumer Empowerment/Involvement

Priority Level		
P	**C**	**Recommendation**
Med	High	Offer follow-up services to those who test positive for the disease or trait. **Implementation Options** DPH's Newborn Screening Program contacts the families of babies who test positive for the disease; the Comprehensive Sickle Cell Treatment Centers; and the baby's pediatrician. DPH works collaboratively with the HRSA-funded Enhance SC Trait Follow -up Services. The process implemented involves DPH referring families with babies who tested positive for the trait to community-based certified counselors or peer educators who offer support, education and serve as a referral source for identified family needs. **Comment/Cost Estimate** Process described above operates with DPH and HRSA support. HRSA support is in the beginning of its second year of a three-year funding cycle. Ongoing support will need to be sought and secured prior to the end of the HRSA contract period (May 2008). Cost note: screening is $3.00 a person plus postage.
P	**C**	**Recommendation**
Med	Low	Develop and carry out an ongoing, multi-level media campaign. **Implementation Options** A successful public awareness campaign that educates and provides information on resources and services will require the expertise of media/public relations' experts. Obtaining the services of a PR firm on a pro bono basis, finding a sponsor that will commit to supporting a SCD campaign or seeking funding sources are options for designing and implementing a campaign. The groundwork for an impressive and highly visible media campaign has already started with federal financial support (and with help from former Representative Nancy Johnson's office). Do an inventory of all public awareness, public education and media campaigns conducted to date. Determine how, if appropriate, previous efforts can be incorporated into ongoing efforts **Comment/Cost Estimate** The Statewide Coordination Center's budget includes $30,000 for media campaigns and a $35,000 salary for a Marketing and Development Manager at 50% time.
P	**C**	**Recommendation**
Low	Low	Design and carry out a legislative education and advocacy campaign on both the federal and state level **Implementation Options** Once a decision is made on what legislative support is needed, key legislators should be identified and contacted. The message communicated to legislators needs to be concise and consistent. Simple one-page fact sheets should be developed and disseminated to legislators and others who are supporters of SCDs legislative agenda. **Comment/Cost Estimate** Cost is integrated into the salaries of staff at the Statewide Coordination Center and the two advocacy organizations.

Outreach & Community Based Advocacy And Consumer Empowerment/Involvement

Priority Level		
P	**C**	**Recommendation**
Low	Med	Establish and maintain a 24/7 hotline and an information and referral service **Implementation Options** 211 Infoline, the state's 24/7 telephone information and referral service, is a potential telephone access point for obtaining information on and referrals to SCD/trait related services as well as other support/services needed by individuals with SCD and their families. A hotline serving as an access point for assistance when in a crisis situation needs to be staffed by or have access to individuals with clinical expertise and the ability to assist the caller in accessing services in a timely and efficient manner. **Comment/Cost Estimate** Cost for using 211 Infoline should be minimal and may require a willingness to train telephone call specialists on SCD/trait and to provide backup if needed by an Infoline call specialist. A site that can offer a 24/7hotline service and have an understanding of SCD would require some compensation for offering the service. Contract could be negotiated based on projected number of calls and degree of effort involved in handling and resolving the presenting problems. The Statewide Coordination Center budget has a $20,000 line item for developing and maintaining a telephone hotline service as well as a telephone access point for obtaining information on services for those with SC disease or trait.
P	**C**	**Recommendation**
No Score	Med	Create and maintain a website **Implementation Options** DPH or any organization offering services to people with SCD/trait could be a potential site. The website should also serve as a portal to other relevant sites. **Comment/Cost Estimate** The effectiveness and richness of a website is dependent on keeping the information current and accurate. In order to be a "go to' place for information on support groups, training opportunities, current information on research, etc. there needs to be a commitment to share the information with the web master and that webmaster must maintain the site. The Statewide Coordination Center budget has a $20,000 one time cost for the development of a website and $7,000 annually for ongoing maintenance and support.
P	**C**	**Recommendation**
High	Low	Design and carry out a legislative education and advocacy campaign on both the federal and state level **Implementation Options** A number of support groups are already operating throughout the state in areas where there is high numbers of people with SCD. Additional support groups for young adult SCD patients and their families will be starting through the new DPH grant

Outreach & Community Based Advocacy And Consumer Empowerment/Involvement

Priority Level		
		Comment/Cost Estimate While there are a number of well-attended support groups meeting throughout the state, they are operating without a structure that is needed to ensure sustainability of effort. A statewide planning process related to support groups should be done to: develop protocols for recruiting, training and retaining support group facilitators; determine where meetings are needed and should be held; and establish the cost of holding groups including, but not limited to, food, rental of space, transportation needs, child care needs and stipends for facilitators. Once the information is obtained an annual support group workplan and budget should be developed. A data collection system also needs to be developed to track support group activities and obtain feedback from support group participants. The cost for support groups is integrated into the advocacy organizations' budgets, which includes for each agency, a Coordinator of Community Outreach and Advocacy ($60,000 annual salary) and $5,000 for rental space, food, travel, etc.
P No Score	**C** No Score	**Recommendation** Keep current hard copy directories (for consumers and providers) **Implementation Options** Keeping hard copy directories current is an ongoing and labor- intensive job. 211 Infoline produces both print and electronic directories and is a possible option for producing SCD directories. Once a website is established, the feasibility of putting the hard copy on the website should be explored. **Comment/Cost Estimate** The Statewide Coordination Center budget includes $4,000 for the maintenance of hard copy directories.
P Low	**C** No Score	**Recommendation** Develop and formalize partnership on the local level **Implementation Options** The new DPH grant has a detailed workplan for doing community based work, which will supplement the work being done locally by the advocacy organizations. **Comment/Cost Estimate** The cost for this activity is integrated into the Statewide Coordination Center and advocacy organizations' budgets. This work will include the time of the Statewide Coordination Center's Program Director and Program Coordinator as well as the Executive Directors and Coordinators of Community Outreach and Advocacy at the two advocacy organizations.

Appendix G
CT's Comprehensive Plan to Address Sickle Cell Disease/Trait

Outreach & Community Based Advocacy And Consumer Empowerment/Involvement

Priority Level		
P	**C**	**Recommendation**
No Score	Med	Offer genetic counseling **Implementation Options** Genetic counseling related to SCD/trait is occurring through the HRSA funded CT Community-based Initiative: Enhance Sickle Cell Trait Follow up Services. The need for additional resources for genetic counseling needs to be explored. **Comment/Cost Estimate** There will be a need to find funds to continue the work supported by the HRSA grant after its three-year grant period is over in May 2008. The Statewide Coordination Center's Marketing and Development Manager can assist in searching and securing the funds needed to maintain genetic counseling services after the grant period is over.
P	**C**	**Recommendation**
Low	Low	Provide newborn screening to identify babies with SCD or trait **Implementation Options** This is already occurring through the DPH Newborn Screening Program **Comment/Cost Estimate** The service is supported with DPH funding.
P	**C**	**Recommendation**
Med	High	Offer follow-up information and referrals to families with SCD or trait **Implementation Options** This is already occurring through the HRSA grant & SCOPE activities. See second recommendation under Outreach & Community–Based Advocacy and Consumer Empowerment/Involvement. **Comment/Cost Estimate** Once HRSA support is no longer available, funding will need to be secured to continue the CT Community-based Initiative: Enhance SC Trait Follow up Services. Since the curriculum was designed with HRSA funds, the ongoing cost will be for maintenance of effort which will involve supporting trained counselors and peer educators and offering, with the curriculum already developed, trainings for newly recruited counselors and peer educators. The Statewide Coordination Center's Marketing and Development Manager can assist in searching and securing the funds needed to maintain genetic counseling services after the grant period is over.
P	**C**	**Recommendation**
Med	Med	Offer screening and follow-up counseling through community based outreach efforts **Implementation Options & Comment/Cost Estimate** See recommendation is list.
P	**C**	**Recommendation**
Med	Low	Offer respite care to families with children with SCD **Implementation Options** Work collaboratively with others seeking respite care services, especially in legislative/funding efforts. **Comment/Cost Estimate** Cost is integrated into the Statewide Coordination Center's Program Coordinator position.

Appendix G
CT's Comprehensive Plan to Address Sickle Cell Disease/Trait

Priority Level		Consumer Empowerment/Involvement and Specialty Care Via Primary/ Secondary and/or Tertiary Care
P	**C**	**Recommendation**
No Score	Low	Explore using home visitation resources for patients in need of care that can be provided in the home. **Implementation Options** Preliminary efforts involve researching the state's home visitation resources to determine if there are resources that, with training and support, could provide home visitation services to individuals with SCD. A search through 211 Infoline's community resources inventory should provide the needed information. **Comment/Cost Estimate** Cost to explore home visiting services is integrated into the Statewide Coordination Center's Program Coordinator position.

		Consumer Empowerment/Involvement, Specialty Care Via Primary/Secondary and/or Tertiary Care and Education/Research
P	**C**	**Recommendation**
High	Low	Establish two (North and South) Centers of Excellence (without walls) for SCD/trait. **Implementation Options** Continue the planning process for two regional Centers of Excellence. Share business plan with legislators and potential funding sources. **Comment/Cost Estimate** The cost for two (2) Comprehensive Sickle Cell Treatment Centers of Excellence (Pediatric and Adult Clinical Care) is $3,751,200.
P	**C**	**Recommendation**
Low	Low	Establish advocacy protocols for treating patients with SCD and train patient advocates for implementation at health care facilities **Implementation Options** The new DPH grant includes the establishment of a Patient Advocate and Systems Navigator position. **Comment/Cost Estimate** Each advocacy organization's budget includes a Patient Advocate/Systems Navigator position at an annual salary of $60,000.
P	**C**	**Recommendation**
No Score	Low	Establish protocols for medical homes that care for patients with SCD and train/support providers in implementing them. **Implementation Options & Comment/Cost Estimate** The new DPH grant includes a medical home initiative that will be implemented as a pilot project. **Comment/Cost Estimate** The medical home initiative will be supported by the new Social Work positions at CCMC and YNHH at annual salaries of $65,000.

Appendix G
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Priority Level		Consumer Empowerment/Involvement, Specialty Care Via Primary/ Secondary and/or Tertiary Care and Education/Research
P	**C**	**Recommendation**
High	High	Establish ED protocols for treating patients with SCD and train/support hospitals in implementing them. **Implementation Options** CT Hospital Association is drafting protocols for review by the advocates **Comment/Cost Estimate** The implementation and monitoring of the protocols will be done by the new Patient Advocate and Systems Navigator positions at both advocacy organizations at an annual salary of $65,000.
P	**C**	**Recommendation**
High	High	Provide, within a context of cultural and ethnic sensitivity, education and training to health care providers, including, Staff at CHCs & SBHCs and school nurses Continue the training established through the DPH funded CT Sickle Cell Consortium Lifespan Approach to Education, Care and Support Services Continue to offer the Hemoglobinathy training after the HRSA funding has ended Explore the feasibility of credentialing SCD providers that can then be replicated on a national level **Implementation Options** Work with DPH, the State Department of Education and membership organizations, such as the CT Primary Association (CPCA) and the CT School Based Health Centers Association (SBHCA), to reach and work with community health centers, school based health centers and school nurses. Coordinate activities listed above with new DPH grant's educational components.= **Comment/Cost Estimate** Oversight of all training endeavors will be done by the Statewide Coordination Center's Director of Education and Training at an annual salary of $65,000.
P	**C**	**Recommendation**
High	High	Establish protocols for transitioning patients with SCD from pediatric to adult care and train/support provides in implementing the transitional process **Implementation Options** The new DPH funded grant includes a transitional care initiative. **Comment/Cost Estimate** Oversight of the transitioning of patients will be done by Transition Nurses located at both Centers at an annual salary of $80,000 each.
P	**C**	**Recommendation**
Low	No Score	Explore and support the use of Complimentary and Alternate Medicines (CAMs) **Implementation Options** **T**he use of CAMs can be incorporated into the Chronic Illness Model of Care in the new DPH funded grant. **Comment/Cost Estimate** The cost of using CAMs is integrated into the budgets of the Statewide Coordination Center and the two Centers of Excellence,

Appendix G
CT's Comprehensive Plan to Address Sickle Cell Disease/Trait

Education/ Research

Priority Level		Recommendation
P	C	
No Score	No Score	Develop and formalize partnerships on the international/national level
		Implementation Options
		Increased visibility of CT's efforts via formal and informal relationships with national leaders, involvement with national organizations. presenting at conferences as well as publishing will lead to enhanced and new partnerships
		Comment/Cost Estimate
		$20,000 has been included in each advocacy's organizations ($10,000 each) for scholarships for consumers and staff to attend workshops and conferences.

The priority level is based on the voting process that stakeholders did at the September 21st meeting and that consumers did via fax and email following the September 21 meeting.

The levels are as follows:
For providers (P)
High level = a score from 47 to 32
Medium level = a score from 24 to 10
Low level = a score from 7 to 5

For consumers (C)
High level = a score from 19 to 14
Medium level = a score from 11 to 6
Low level = a score from 5 to 1.

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