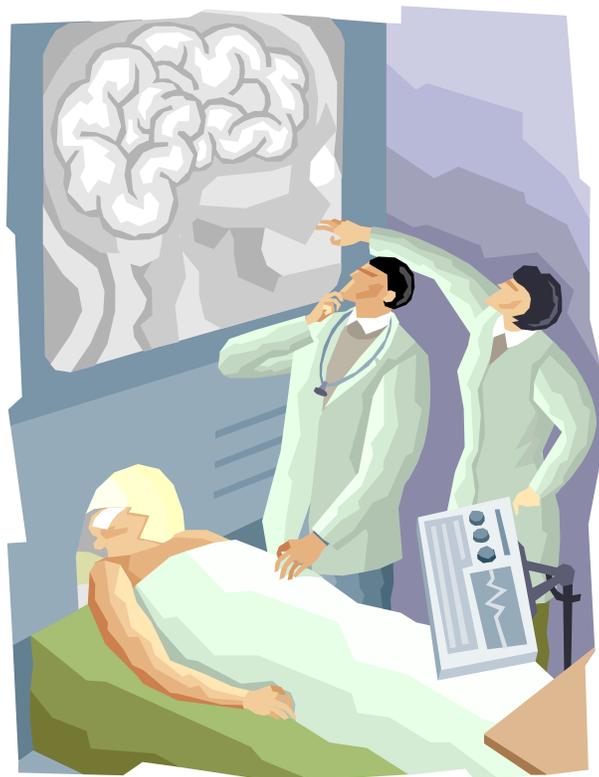


Stroke Systems of Care: A Stroke Prevention and Treatment Strategy for Delaware

GRAY MATTERS

A Report of the Delaware Stroke Task Force

January 2007



The Delaware Stroke Task Force is a Sub-Committee of the Delaware Health Care Commission's Chronic Illness & Disease Management Task Force

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* Appendices 10 – 13 are available electronically upon request. For more information, contact the Health Care Commission at (302) 672-5187.

EXECUTIVE SUMMARY

Leading Cause of Death

Stroke is among the most serious public health challenges facing the State of Delaware and the United States. Sometimes referred to as a brain attack, stroke is the third leading cause of death and a leading cause of adult disability. This devastating illness is a particularly severe problem in Delaware. The U.S. Census Bureau reports Delaware's population of citizens who are 65 years-old and older is greater than the national average, 13.1% in Delaware versus 12.4% in the United States, and the incident rate for Stroke increase with age, as illustrated in Table 1 below:

Table 1. Delaware Health and Social Services, Division of Public Health

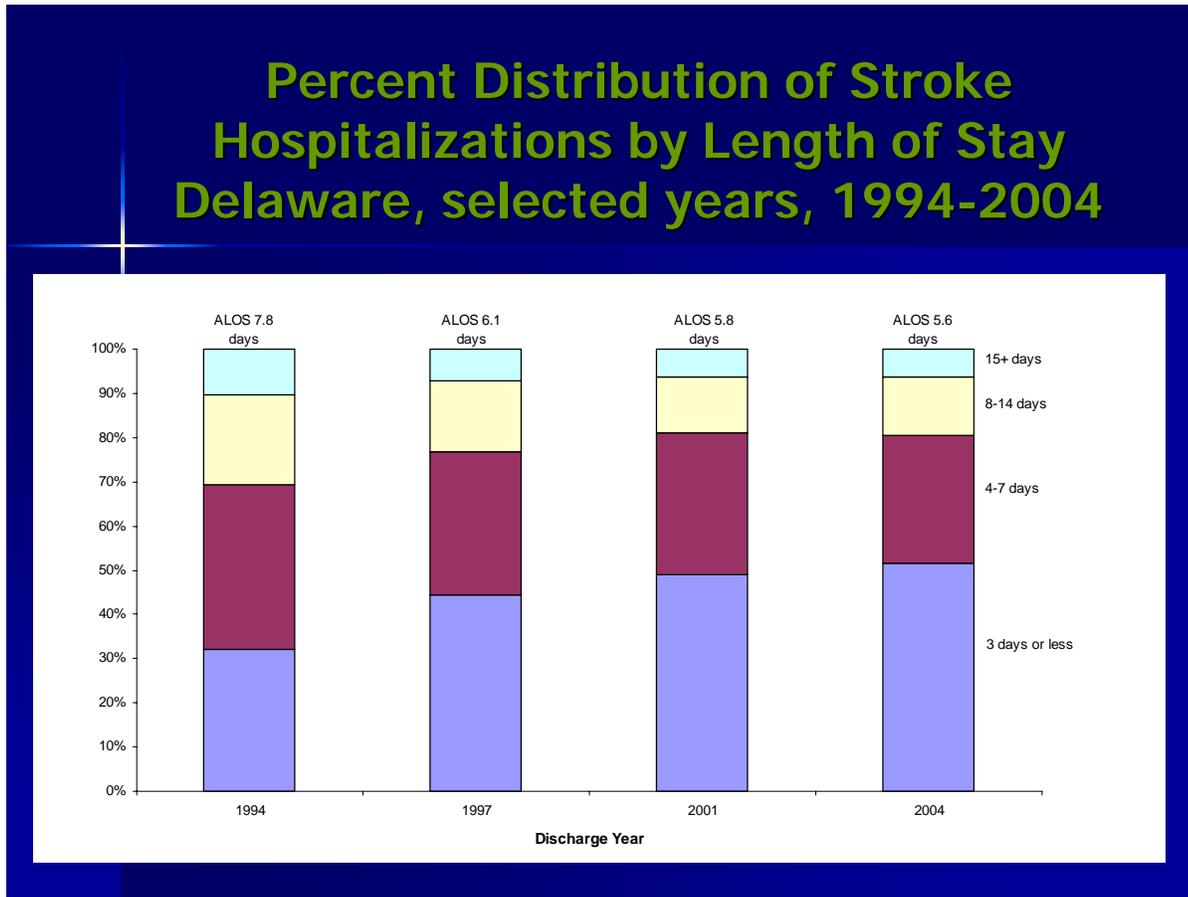
<h2 style="text-align: center;">Number and Rate of Delaware Resident Discharges due to Cerebrovascular Disease: Delaware, 2004</h2>												
	All ages		<15		15-44		45-64		65+		ALOS in Days	
	Number	Rate	Number	Rate	Number	Rate	Number	Rate	Number	Rate		
All Races	2348	28.3	2	0.1	110	3.2	590	28.8	1646	143.7	5.8	
Males	1105	27.5	2	0.2	49	2.9	290	29.4	764	156.5	6	
Females	1243	29	0	0	61	3.5	300	28.3	882	134.2	5.7	
White	1786	29	2	0.2	52	2.1	386	23.9	1346	135.7	5.3	
Males	839	28.1	2	0.4	24	2	191	24.2	622	146.6	5.5	
Females	947	29.8	0	0	28	2.3	195	23.5	724	127.6	5.2	
Black	502	29.3	0	0	54	6.9	181	50.8	267	202.4	7.6	
Males	229	28.1	0	0	23	6.1	86	52.8	120	222.3	8.1	
Females	273	30	0	0	31	7.6	95	49.1	147	188.7	7.1	

Rates are crude and age-specific rates, per 10,000 population. In 2004, females of both races had higher hospitalization rates than males. Hospitalization rates for stroke are very similar across race and sex categories, but they differ a great deal between age groups, with the 65+ group having the highest rate of discharges. ALOS refers to the average length of stay at the hospital in days.

LEADING CAUSE OF DISABILITY

Stroke is the 3rd leading cause of death and a leading cause of disability. In addition to the social policy and public health implications, there is a significant negative economic impact to the patient, their families and the entire spectrum of the health care delivery system.

Table 2. Delaware Health and Social Services, Division of Public Health



The average length of stay (ALOS) decreased 29.1%, from 7.8 in 1994 to 5.6 in 2004. The decrease in ALOS was accompanied by a shift in the distribution of length of stay toward shorter hospital stays. In 2004, the average charge for a stroke hospitalization was \$15,607.00.

As the population of Delaware continues to age, the incidence of Stroke and the resulting number of death and disabilities are likely to increase.

RESPONSE TO STROKE

The first maxim among professionals who face the challenge of stroke is this: ***The best way to treat a stroke is to prevent it.*** A new Stroke Office, Vascular Disease Unit would greatly assist in the implementation of preventive efforts that address the specific requirements of underserved urban and rural populations. In addition, they can ensure that preventive efforts are tailored to the cultural backgrounds and other characteristics of the public intended to be served. Currently, 32 states and the District of Columbia receive CDC funding for State Heart

Disease and Stroke Prevention Programs, 19 as capacity building programs and 14 as basic implementation programs. Delaware *does not* currently receive CDC funding for this type of program. A primary recommendation of this report is to have Delaware apply for the CDC funding.

In 1998, the U.S. Congress first provided funding for CDC to initiate a national, state-based heart disease and stroke prevention program with funding for eight states that included capacity building criteria, such as:

- Develop and update a comprehensive state plan for heart disease and stroke prevention by developing heart-healthy policies, changing physical and social environments and eliminating disparities (e.g., those based on geography, gender, race or ethnicity, or income)
- Increase awareness of the signs and symptoms of heart attack and stroke
- Promote enhanced policies for *treating stroke as an acute emergency*

The next essential component of a comprehensive stroke treatment and prevention system is an acute care structure that takes the maximum realistic advantage of the new therapies and responds to the need to administer **treatment within three hours of onset**.

Finally, the stroke program must address the needs of **stroke survivors**. Many survivors need extensive rehabilitation services, and the earlier the services are provided, the more likely the patient can preserve function and maintain independence.

CURRENT DELAWARE STROKE STRATEGIES

Delaware is fortunate to have several excellent strategies in place to address the challenge of stroke with considerable success. These diligent efforts occur in both the private and public sectors by professionals and volunteers who deserve our gratitude and support. Some of the outstanding success has been demonstrated through hospital and physician collaborations, Delaware Department of Health and Social Services, Delaware Health Care Commission, Delaware Emergency Management Services (EMS), Volunteer Fire and Ambulance entities, Delaware Stroke Initiative, American Heart Association and American Stroke Association, just to name a few.

Of all the tremendous efforts to create statewide stroke initiatives, Delaware's EMS has excelled in developing best practice standards that include, but are not limited to:

- All dispatchers must be certified Emergency Medical Dispatchers (EMDs).
- All 911 call centers are required to use the Priority Medical Dispatch System (PMDS)
- Paramedics in Delaware **MUST** attend state approved continuing education programs.
- Transport to the nearest appropriate **CT-capable** medical facility without delay

However, more must be done to establish consistent, evidence-based standards across the spectrum of stroke education, treatment and rehabilitation for all the citizens and visitors to Delaware.

In addition to its high incidence and devastating effects, two other factors have caused greater attention to be paid to stroke. Recent advances in treatment, including the emergence

of thrombolytic drug therapies (such as tPA), have made it possible to limit the damage caused by some strokes. However, these therapies must be administered rapidly after the onset of symptoms to be effective, usually within the first critical three hours. Consequently, the stroke care community must develop a new approach to the structure of stroke treatment and must educate the public about the need to treat stroke as an immediate medical emergency.

A second factor is proposed federal legislation called the Stroke Treatment and Ongoing Prevention (STOP) Act that would provide block grant funding for stroke prevention and treatment. The legislation contemplates a phased in appropriation rising from \$50 to \$125 million, contingent in later years on matching state appropriations. If this legislation is enacted, Delaware will need to have a stroke prevention, treatment and rehabilitation structure in place to qualify for federal funding. However, even if the federal STOP STROKE ACT does not provide funding, the need to address Stroke Care System in Delaware must not be forgotten.

HISTORY

Delaware Health Care Commission assembled the Delaware Stroke Task Force at the request of four distinguished members of Delaware's General Assembly: Representative Bethany Hall-Long, Representative Pam Maier, Senator Patricia Blevins, and Senator Dorinda Connor.

Their request, dated December 5, 2005, was addressed to the Delaware Health Care Commission, and stated the following, "Given the impact of stroke in Delaware, we believe it would be appropriate to develop a stroke system of care in Delaware through the Chronic Illness and Disease Management Task Force (Task Force) or Health Care Commission. Other states have created – through legislation – Stroke Task Forces to develop statewide stroke systems of care. We believe it is not necessary to pursue a legislatively created stroke task force to develop statewide stroke systems but rather work through this existing Task Force and/or Health Care Commission. The Task Force's charge and recommendations make the Task Force an appropriate body to develop a statewide stroke system."

In response, the Delaware Health Care Commission and the Chronic Illness and Disease Management Task Force created the Delaware Stroke Task Force to explore the current environment, identify potential areas of excellence as well as gaps in stroke care systems, and make recommendations to develop and improve Delaware's statewide stroke systems. The Stroke Task Force included experts in various related fields from all three counties to draw upon their knowledge and experience working together to improve Delaware's response to stroke. They divided into five sub-committees, focused on specific aspects of the stroke care systems: Primordial & Primary Prevention; Emergency Medical Services; Acute & Sub-Acute Stroke Care; Rehabilitation; and Continuous Quality Improvements. Their recommendations are set forth in this report and their critical findings are briefly summarized below.

The report includes a summary of data relating to stroke incidence and death rates, data on risk factors affecting stroke, a description of current stroke care systems in Delaware and a vision for improving the outcomes for stroke victims.

Critical Findings:

- 2.5% of Delaware adults say they have been told they had a stroke.
- Estimated 15,560 living Delaware adults who report having had a stroke.
- There were differences in the death rates due to stroke and trends among the three counties (New Castle, Kent, and Sussex).
- Mortality rates due to stroke were relatively higher in Kent than in New Castle and Sussex during the period 1989 to 2000.
- Mortality rates continued to decline in the Kent and Sussex counties, while in the New Castle county there was a decline during the period from 1989 until 1997, increased slightly after that and assumed a plateau until 2003.
- Among Delaware adults who report having had a stroke, 25% said they were current smokers. Another 32.8% reported being former smokers.
- 42% of stroke victims in the survey said they had never smoked compared with 50% of people who did not have a stroke.
- The smoking link may be more dramatic than it seems: because smoking-related deaths from heart disease tend to occur at younger ages than strokes, many smokers may have died earlier from other diseases – e.g. heart attacks, emphysema, or lung cancer.
- Among Delaware adults who are obese, about twice as many reported having a stroke.
- Among Delaware adults who have diabetes, the relationship is even more dramatic. Only 2.5% of adults without diabetes reported having a stroke. However, 10.1% of diabetics reported having a stroke (and 9.3% of pre-diabetics)
- During 2005, paramedics in Delaware treated and transported,
 - 6453 patients with head injury
 - 592 patients with non-hypoglycemic altered mental status
 - 1206 patients with seizures, 176 (15%) were treated for epileptic status.
 - 1160 patients with stroke
 - 1233 patients with syncope (temporary loss of consciousness)

Sub-Committee Notes

Complete sub-committee notes are included as appendices to this report. Also included are extensive reports and data on each stage of stroke treatment, compiled from various sources, including but not limited to Emergency Medical Services Office, Division of Public Health, Chronic Disease Bureau, Delaware Health Care Association, Delaware Health Care Commission, American Stroke Association, a division of American Heart Association and the Delaware Stroke Coalition.

Delaware Hospital Survey Results:

One of the recommendations from the sub-committee on Acute and Sub-Acute Care is to conduct a comprehensive analysis of Delaware's stroke system capacity. A preliminary survey was administered in October 2006 to all of the hospitals in Delaware to assess basic stroke treatment capabilities for the purpose of this report. The results have been provided by the Delaware Healthcare Association and may be found on Page 11.

Delaware Hospital Name ¹	City	Does hospital have a Stroke Unit?	Does hospital have a Stroke Team?	Is TPA available for treatment?	Is there a written protocol for treatment of stroke with TPA?	Is computed tomography (CT Scan) of the head available 24 hours a day?	Is a neurosurgeon available at your hospital?	Neurologist on-call 24-hours a day to treat patients?	Does hospital have written guidelines for evaluation and treatment of stroke?	Estimated number of stroke patients seen in 2005
Al DuPont Children's Hospital	Wilmington	NO	NO	NO	NO	YES	YES	YES	NO	Very rare - difficult to estimate
Bayhealth - Kent General Hospital	Dover	NO	NO	YES	NO	YES	NO	YES	NO	152
Bayhealth - Milford Hospital	Milford	NO	NO	YES	NO	In-house CT tech until 1am, then on-call tech with a 30 minute availability	NO	YES	NO	61- over 6 month period
Beebe Medical Center	Lewes	NO	Currently developing- Have a champion & members established and are writing protocols	YES	YES	YES	NO	YES	In process of establishing new guidelines	184
CCHS ² – Christiana Hospital	Stanton	YES	YES	YES	YES	YES	YES	YES	YES	850
CCHS - Wilmington Hospital	Wilmington	NO	YES	YES	YES	YES	YES	YES	YES	200
Veterans Affairs Hospital	Wilmington	NO	NO	NO	NO	NO	NO	YES	NO	10-15 new stroke patients per year
Nanticoke Memorial Hospital	Seaford	NO	NO	YES	YES	YES – Also developed an expedited protocol for its use in stroke & potential TPA	NO	NO	YES - for TPA candidates	270
St. Francis Hospital	Wilmington	YES	YES	YES	YES	YES	YES	YES	YES	100

¹ Survey results provided by Delaware Healthcare Association (November 2006)

² CCHS = Christiana Care Health System

RECOMMENDATIONS FOR DELAWARE STROKE SYSTEM OF CARE

RECOMMENDATIONS AT-A-GLANCE:

- ***Stroke Office and Stroke Coordinator***
- ***Data Sharing & Stroke Registry***
- ***Prevention***
- ***Public Awareness & Education Campaign***
- ***Research & Continuing Education***
- ***Statewide Standards***
- ***Optimal Patient Care: from onset of symptoms to rehabilitation***
- ***Funding***
- ***Performance Measures***

PRIORITY RECOMMENDATIONS:

(For full sub-committee reports, see appendices beginning on Page 38.)

Stroke Office

- Creation of a Stroke Office within a Vascular Disease administrative unit under the Bureau of Chronic Disease, Division of Public Health that would be responsible for vascular diseases, including cardiovascular disease and stroke, which could perform the functions recommended in this report. Potential funding sources include State Master Tobacco Settlement funds, grants from the Centers for Disease Control & Prevention (CDC), and funding made available pending the passage of the federal Stop Stroke Act.
- Because of the particular urgency of stroke as a public health problem in Delaware, a Stroke Office should be established with the specific purpose to coordinate statewide efforts for stroke prevention, treatment, and rehabilitation programs, disseminate best practices and other information, and conduct research. The Office should be led by a Stroke Coordinator and guided by a representative multidisciplinary advisory committee. Adequate resources should be committed to enable the Office to lead Delaware's response to stroke.

Data Sharing & Stroke Registry

- Assess the collection, analysis and use of existing data and enhance data sharing opportunities to facilitate medical research related to stroke prevention/treatment and to develop best practices. The Stroke Coordinator would act as a catalyst to move Delaware toward the long-term goal of developing a Stroke Registry to track all phases of stroke care as well as long-term patient outcome data by exploring current and future data sharing systems, including but not limited to the Delaware Health Information Network (DHIN) statewide clinical information sharing utility.

Prevention (Activities to be functions of the new Stroke Office)

1. Make available to health professionals the best practices for preventive care and establish a clearinghouse for stroke research and information. Explore methods to increase stroke screenings and public education about stroke through partnering with organizations such as the Delaware Stroke Initiative.
2. Promote screening and education about blood pressure, cholesterol, blood sugar, and risk factors (smoking, diabetes, etc.) to all primary care and non-traditional primary care providers, such as OB-GYN, nurse practitioners, community health clinics, etc.
3. Study strategies for expanding the availability of insurance coverage for diagnostic services and preventive care for stroke, as well as education of insurance companies regarding the cost effectiveness of providing coverage for preventive treatments, such as nutritional counseling and increased physical activity.

Public Awareness & Education Campaign

- Establish educational programs to raise awareness of the signs and symptoms of stroke. Emphasize the recognition of risk factors (hypertension, smoking, high cholesterol, diabetes, and drug use) to help increase early preventive interventions.
 - Use a variety of media outlets in English and Spanish, targeting diverse audiences (urban/rural, gender, age, race/ethnicity, etc.)
 - Include stroke resource guides, smoking cessation materials, and obesity prevention/healthy eating techniques
 - Inform potential victims, their caregivers, first responders and acute/sub-acute medical professionals to:
 - Recognize signs/symptoms of stroke;
 - Treat stroke and TIA (mini-stroke) as medical emergencies;
 - Obtain immediate medical assistance using 9-1-1, recognizing that a 3-hour window of opportunity exists for critical treatment.

Notification & Response of Emergency Medical Services

1. Implement a data exchange system between the Delaware Office of Emergency Medical Services (OEMS- within the Division of Public Health) and hospital emergency departments to track outcomes for stroke survivors. Close the data gap.
2. Continue the use of a uniform pre-hospital screening/rapid detection tool by emergency first responders. Routinely evaluate available tools to determine the optimal means of conducting pre-hospital screening with methods that represent current research and positive patient outcomes.
3. Enhance education and certification of emergency medical dispatchers & emergency medical services personnel. Develop alternative delivery methods to accommodate the volunteers' schedules such as on-line or off-site trainings, i.e. videos, DVDs, etc.

Acute Care & Sub-Acute Care

1. Conduct a comprehensive, in-depth study of Delaware's stroke system capacity, including emergency departments, acute and sub-acute care providers, specialists, etc. Assess the capability of existing health care facilities (treatment options, equipment, space, staffing, etc.). Based on the assessment, share findings with emergency medical services, neurologists and hospitals to formulate a statewide plan to allow optimal triage and treatment of stroke survivors.
2. Explore transfer options to respond to strokes that are beyond a facility's capability to treat. Evaluate options for emergency evaluation, triage and transfer of patients among in-state facilities as well as out-of-state transfers for patients requiring specialized care available only at tertiary medical centers.
3. Establish a long-term goal of improving acute care capacity such that no Delaware resident lives more than one hour away from a health care facility with capability of providing high quality treatment for acute strokes.
4. Establish quality initiatives and continue to promote best practice models to expedite diagnosis and care, utilizing evidence-based guidelines developed by national organizations and in cooperation with the Medical Society of Delaware. Continue to research acute therapy options, post treatment interventions, and the feasibility of new treatment modalities as they become available.

Rehabilitation

1. Determine and document which pathway of care provides the greatest likelihood of improved function in individuals post-stroke. It is critical that stroke survivors' functional progress be accurately tracked as they move through the health care system and to different treatment settings so that the most optimal pathway for particular levels of initial impairment and function can be identified. This initiative relies on the use of information collected by a cardiac and stroke event registry using industry standards to track survivors' recovery and progress. Also, consider collecting data from the Activity Measure for Post-acute Care (AMPAC), based on International Classification of Function (ICF) standards, for survivors at each point along a given treatment pathway.
2. Promote awareness and utilization of evidence-based rehabilitation guidelines by making continuing education opportunities and professional journals on stroke rehabilitation more accessible to rehabilitation therapists.
3. Increase the supply of occupational and speech therapy professionals in more remote regions of the state where patients often have to wait up to a month or more before obtaining access to these disciplines because of the shortage of these health professionals in the state.
4. Research and explore opportunities with major insurance carriers operating within the State of Delaware regarding the possibility of allocating some of their end-of-year reserve for stroke care as a carve-out diagnosis and encourage them to help collect data on the AMPAC on patients insured by them. In addition, perform a comprehensive study of insurance coverage for rehabilitation to inform carriers of the types of coverage and benefits that can reduce over-utilization of nursing homes.

5. Communicate with Delaware's Congressional Delegation and State leaders regarding potential impact of the Centers for Medicare & Medicaid Services recent call for a demonstration project that will develop and assess the effectiveness of post-acute care assessment instruments, to ensure that Delaware is well positioned to participate in the pilot demonstration.

FUNDING

Implementing these recommendations will require a substantial commitment of financial resources. In the present constrained fiscal environment, a variety of funding sources must be tapped to support a major initiative such as that outlined in this report, including creation of public-private partnerships. In addition to the proposed federal STOP Stroke Act, another potential source of funding may be through special appropriated funds possibly made available through an increase in tobacco excise tax and/or a dedicated lottery. The Stroke Office would be responsible for seeking funding opportunities through appropriate foundations and medical charities. An immediate goal is to prepare Delaware's application for CDC funding, as described on page 9 of this report.

The Stroke Task Force believes that directing funds and efforts toward enhancing stroke prevention and care will produce a return on investment by helping more Delawareans achieve longer, healthier lives, free of the tragic effects of stroke that darken the lives of our citizens and families. In addition, Delaware's health care economic burden will be decreased in direct correlation with a decrease in stroke incidence.

PERFORMANCE MEASURES

A stroke system should strive to optimize the overall effectiveness of the system and each of its individual components. This goal should be accomplished by identifying performance measures for each component and for the system function as a whole (both process and outcome measures) and by employing Continuous Quality Improvement (CQI) strategies in collaboration with key stakeholders. Both process and outcome measures will be developed to measure implementation of services, linkages among key stroke system components, obstacles to care, potential gaps, and most importantly - patient outcomes. (Measures are listed on the following page.)

Performance Measures		
Stroke Plan Component	Measure Type	Measure Description
Primordial and primary prevention	Process	<ul style="list-style-type: none"> Reach of distribution of new stroke prevention strategies Number of providers aware of emerging stroke prevention strategies Number of providers implementing in a systematic way the emerging strategies (pre/post intervention)
Primordial and primary prevention	Process	<ul style="list-style-type: none"> Reach of community education activities, especially among at-risk populations Percent change in knowledge and attitudes about the causes, signs and symptoms of stroke among sample population
Primordial and primary prevention	Outcome	<ul style="list-style-type: none"> Number of deaths averted due to early sign/symptom awareness
Notification of Emergency Medical Services	Process	<ul style="list-style-type: none"> Development of data exchange system between EMS and hospitals (yes/no) Data quality as measured by inter or intra-rater reliability assessment Time to CT capable emergency room
Notification of Emergency Medical Services	Outcome	<ul style="list-style-type: none"> Increase # of stroke victims who present in ER Dept. w/in 3 hours of symptom onset
Acute and sub-acute stroke treatment	Process	<ul style="list-style-type: none"> Time between identification of stroke and delivery of acute treatment of both ischemic and hemorrhagic stroke
Acute and sub-acute stroke treatment	Outcome	<ul style="list-style-type: none"> % increase in positive patient outcomes due to appropriate tPA use % decrease in complications prevented due to effective acute treatment
Rehabilitation	Process	<ul style="list-style-type: none"> Number of stroke survivors who receive and initial evaluation for rehab therapy during initial hospitalization Care plans for stroke survivors discharged from hospitals including identified support systems, primary and follow-up care
Rehabilitation	Outcome	<ul style="list-style-type: none"> % decrease in mortality % of stroke survivors who recover activities of daily living

INTRODUCTION

This report is a product of Delaware Stroke Task Force. Delaware Health Care Commission assembled the Delaware Stroke Task Force at the request of four distinguished members of Delaware's General Assembly: Representative Bethany Hall-Long, Representative Pam Maier, Senator Patricia Blevins, and Senator Dorinda Connor.

Their request, dated December 5, 2005, was addressed to the Delaware Health Care Commission, and stated the following, "Given the impact of stroke in Delaware, we believe it would be appropriate to develop a stroke system of care in Delaware through the Chronic Illness and Disease Management Task Force or Health Care Commission. Other states have created – through legislation – Stroke Task Forces to develop statewide stroke systems of care. We believe it is not necessary to pursue a legislatively created stroke task force to develop statewide stroke systems but rather work through this existing Task Force and/or Health Care Commission. The Task Force's charge and recommendations make the Task Force an appropriate body to develop statewide stroke systems."

In response, the Delaware Health Care Commission and the Chronic Illness and Disease Management Task Force created the Delaware Stroke Task Force to explore the current environment, identify potential areas of excellence as well as gaps in stroke care systems, and make recommendations to develop and improve Delaware's statewide stroke systems.

The Stroke Task Force included experts in various related fields from all three counties to draw upon their knowledge and experience working together to improve Delaware's response to stroke. They divided into five sub-committees, focused on specific aspects of the stroke care systems: Primordial & Primary Prevention; Emergency Medical Services; Acute & Sub-Acute Stroke Care; Rehabilitation; and Continuous Quality Improvements. Between the full meetings of the Stroke Task Force, each of these subcommittees met to provide guidance in their respective areas.

While published sources are cited for many points in this report, the conclusions and recommendations depend heavily on the expertise, wisdom, and experience of the Stroke Task Force members.

MEDICAL AND ECONOMIC CONSEQUENCES³

- On average, every 45 seconds someone in the United States has a stroke.
- On average, about every 3 minutes someone dies of a stroke.
- 8-12% of ischemic strokes and 37-38% of hemorrhagic strokes result in death within 30 days.

A stroke can hit without warning. Within moments, the victim can be wrapped in a shroud of darkness and excruciating pain, unable to communicate with the people around them. Or the victim may feel weak or numb on one side and lose their orientation. The potential stroke risk

³ American Heart Association-American Stroke Association "Heart Disease & Stroke Statistics 2006 Update: Appendix 13 americanheart.org/downloadable/heart/1136308648540Statupdate2006.pdf

increases as our population ages and unhealthy behavior characteristic of modern life continue to take their toll.

A TIA, or transient ischemic attack, is a mini-stroke that lasts less than 24 hours.

Approximately 15 percent of all strokes are heralded by a TIA.

Approximately half of patients who experience a TIA fail to report it to their health care providers.

Within a year of TIA, up to a quarter of patients will die.

14 percent of persons who survive a first stroke or TIA will have another one within one year.

22 percent of men and 25 percent of women who have an initial stroke die within a year.

51 percent of men and 53 percent of women under age 65 who have a stroke die within eight years.

The length of time to recover from a stroke depends on its severity. Between 50 and 70 percent of stroke survivors regain functional independence, but 15 to 30 percent are permanently disabled, and 20 percent require institutional care at three months after onset.

Among ischemic stroke survivors who were at least 65 years old, these disabilities were observed at six months post-stroke:

- 30 percent were unable to walk without some assistance.
- 26 percent were dependent in activities of daily living.
- 35 percent had depressive symptoms.
- 26 percent were institutionalized in a nursing home

INCIDENCE AND DEATH RATES

The statistics that describe the impact of stroke are frightening. Stroke is the third leading killer in both the United States and Delaware and is one of the leading causes of adult disability. Every year approximately 500,000 people suffer their first strokes and an additional 200,000 experience recurrent strokes nationwide leaving to date about 4.6 million survivors, many with severe disabilities. Stroke accounted for about one of every 15 deaths in the United States in 2003. About 50 percent of these deaths occurred out of hospital.³

The critical elements of this plan related to prevention, awareness and education, 911 Dispatch, Emergency Medical Services, first responders and care givers are essential to decreasing the stroke deaths in patients who do not get to the hospital in time.

Table 3 - Delaware Division of Public Health

Frequency of Stroke Deaths by county, race, and sex

1999 - 2003

Area	DE	1994
	Kent	302
	NCC	1248
	Sussex	444
Race	White	1663
	Black	318
Sex	Male	773
	Female	1221

In 2004, Delaware saw 2,348 hospitalizations for stroke, according to the discharge rates provided by the Delaware Division of Public Health.

Rural and underserved urban populations are subject to particular risk. Many rural residents are beyond the major urban centers and out of the immediate reach of cutting edge stroke treatments. In urban areas, cultural differences can become obstacles that keep some people from accessing proper stroke education, preventive treatment, and acute care. These are important considerations when creating a state-wide stroke care system that will meet the needs of the rural communities throughout Sussex County as well as the urban and suburban communities, located in Kent and New Castle Counties.

ADDITIONAL DATA

The appendices to this report include data that may be of interest in analyzing issues relating to stroke.

ECONOMIC COSTS

According to American Heart Association (AHA), as illustrated in the following exhibit, the cost of strokes to the nation is projected to be about \$57.9 billion in 2006, including direct costs of \$37.3 billion and indirect costs of \$20.6 billion. AHA does not break down total national cost by state. Instead, a rough estimate of how much Delaware will spend on strokes in 2006 is made by a cost estimation method that applies Delaware’s percentage of the total population of the United States to the total national cost of stroke.

Table 4 – American Heart Association “2006 Heart and Stroke Statistical Update”

Estimated Direct and Indirect Costs (in Billions of Dollars) of Cardiovascular Diseases and Stroke						
United States: 2006						
	Heart Diseases**	Coronary Heart Disease	Stroke	Hypertensive Disease	Heart Failure	Total Cardiovascular Disease*
Direct Costs						
Hospital	\$81.3	\$41.8	\$15.5	\$6.2	\$15.4	\$114.8
Nursing Home	20.7	10.9	14.3	4.2	3.9	42.6
Physicians/Other Professionals	19.7	11.1	3.1	11.0	2.0	38.3
Drugs/Other						
Medical Durables	21.2	9.8	1.3	24.4	3.1	50.1
Home Health Care	5.2	1.6	3.1	1.7	2.4	11.8
Total Expenditures*	\$148.1	\$75.2	\$37.3	\$47.5[‡]	\$26.8	\$257.6
Indirect Costs						
Lost Productivity/Morbidity	21.9	9.6	6.4	7.7	—	35.6
Lost Productivity/Mortality ^{##}	88.5	57.7	14.2	8.3	2.8	109.9
Grand Totals*	\$258.5	\$142.5	\$57.9	\$63.5	\$29.6	\$403.1

Note: (–) = data not available.

* Totals do not add up due to rounding and overlap.

** This category includes coronary heart disease, heart failure, part of hypertensive disease, cardiac dysrhythmias, rheumatic heart disease, cardiomyopathy, pulmonary heart disease, and other or ill-defined “heart” diseases.

Tom Hodgson and Liming Cai (Medical Care 2001) estimated that healthcare expenditures attributed to hypertension that could be allocated to cardiovascular complications and other diagnoses totaled \$108 billion in 1997.

Lost future earnings of persons who will die in 2006, discounted at 3 percent.

Sources: Hodgson TA, Cohen AJ. Medical care expenditures for selected circulatory diseases: opportunities for reducing national health expenditures. *Medical Care* 1999;37:994–1012.

National Health Expenditures Amounts, and Average Annual Percent Change, by Type of Expenditure: Selected Calendar Years 1990–2013 (cms.hhs.gov).

Rice DR, Hodgson TA, Kopstein AN. The economic costs of illness: a replication and update. *Health Care Financ Rev* 1985;7:61–80.

Historic Income Tables – People (census.gov).

Deaths for 358 Selected Causes by 5-Year Age Groups, Race, and Sex, United States, 2002 (cdc.nchs/default/htm).

Rice, Max, Michel, and Sung. Present Value of Lifetime Earnings, U.S. 2003. Unpublished tables, Institute for Health and Aging, University of California, San Francisco, 2005.

All estimates prepared by Thomas Thom, NHLBI.

Using this approach, the total cost of strokes in Delaware in 2006 will be approximately \$115,800,000 (\$57.9 billion x .002). This estimation method may not accurately reflect Delaware’s costs because it ignores the relative age of our population as compared to the United States.

Population estimates⁴		
Geographic Area	July 1, 2003	Percentage
United States	290,809,777	100%
Delaware	817,491	.0028%

⁴ <http://www.census.gov/Press-Release/www/2003/cb03-197table1.xls>

NATURE AND TYPES OF STROKE

A stroke is a medical episode during which blood flow to the brain is reduced or blocked by an arterial obstruction or rupture. An ischemic stroke is caused by a blockage or narrowing in an artery that prevents blood from flowing to brain tissue. This can occur in the brain itself or at some point along the blood's path to the brain. A cerebral embolism occurs when a wandering clot (embolus) or other particle forms in a blood vessel away from the brain, usually in the heart. The clot is carried in the bloodstream until it lodges in an artery leading to or in the brain, blocking the flow of blood. Cerebral thrombosis occurs when a stationary blood clot (thrombus) forms and blocks blood flow in an artery carrying blood to the brain.

A hemorrhagic stroke occurs when a rupture in an artery diverts blood flow from the brain tissue it normally supplies. The pressure of blood leaking into brain tissue can damage or kill neurons. In a cerebral hemorrhage, bleeding occurs when a defective artery in the brain bursts, flooding the surrounding tissue with blood and preventing blood from reaching its destination. In a subarachnoid hemorrhage, bleeding occurs when a blood vessel on the brain's surface ruptures and bleeds into the space between the brain and the skull, but not into the brain itself. This prevents the blood from reaching areas of the brain and also puts pressure on brain tissue. Hemorrhagic strokes account for 17% of all strokes and are even more devastating than the ischemic type.

Transient ischemic attacks (TIAs) are viewed as mini-strokes, although there is emerging evidence that they may occur through mechanisms different from those resulting in strokes. A TIA is a brief condition where blood is temporarily cut off from reaching the brain, often by an arteriosclerotic condition. A TIA mimics many of a stroke's symptoms such as numbness, muscle weakness, and speech or language difficulties, but the symptoms usually last about an hour, although they may persist up to 24 hours. Nonetheless, TIAs are closely correlated with the occurrence of strokes.

CONSEQUENCES OF STROKE

The severity of a stroke depends on the amount of brain tissue affected as well as the location in which it occurs. A relatively small stroke can be fatal or catastrophic if it hits an area of the brain that controls life sustaining functions, such as those contained in the brain stem. ASA lists the following five symptoms of stroke:

- Sudden numbness or weakness of the face, arm or leg, especially on one side of the body
- Sudden confusion, trouble speaking or understanding
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- Sudden, severe headache with no known cause.

Any one of these signs can signal danger, and it is vital that anyone experiencing one or more of them get medical attention immediately.

Right Hemisphere Strokes

Right hemisphere strokes can lead to difficulty in performing the routine activities of life, such as bathing, eating, and dressing. A victim may be unable to button his shirt, tie his shoes, find her way to the restroom or perform other routine but complex, coordinated movements. In some cases, the victim is affected by a loss of left-field vision. In one example cited, a patient

was unable to see a shirt lying on the left side of his room without turning his head, and therefore assumed it was missing.

A condition known as neglect is also characteristic of right hemisphere strokes. Neglect, or more accurately neglect of the left side, is exhibited in different ways. A victim may neglect to shave the left side of his face, or, when asked to draw a clock face, draw only the right side. Even in reading and speaking, a word's left syllable may be ignored. For example, a person may see or say the word "word" when "crossword" is appropriate. A patient may neglect, or deny, that he had a stroke in the first place, which can hinder recovery. A patient may even attribute a paralyzed limb to another person. Visual memory problems may also affect a stroke victim. A person who suffers these problems may have little or no ability to recall visual information, even immediately after seeing it.

Right brain stroke survivors often have difficulty with the nuances of language use. They may have difficulty interpreting emotions or humor, abstract information and non-verbal body language. They may speak excessively or have trouble taking turns in conversation. Their speech may be flat with limited inflection. Poor judgment can also show up as a symptom of right hemisphere stroke. The difficulties with visual perceptions, visual memory, and neglect can combine with time disorientation and impaired abstract thinking. Poor judgment caused by a stroke can be particularly troubling with regard to safety issues, such as are associated with operating a motor vehicle. Extreme emotional swings, from happiness to sadness in a matter of seconds, are also characteristic of right brain strokes.

Left Hemisphere Strokes

A left brain stroke is characterized by weakness, numbness or paralysis on the right side of the body. Right field vision can also be affected or lost, as is left side vision with right brain strokes. Aphasia often results from left brain stroke. Aphasia is the loss or impairment of the ability to use or comprehend language. Aphasic individuals may have difficulty forming words or sentences. They may repeat the same phrase over and over or may only be able to produce nonsense words. Such victims may have trouble thinking of words or substitute a related word for the one they are trying to say. They may have difficulty understanding what others say to them or comprehending reading. Some individuals may also experience apraxia, which is a motor planning problem in which they have difficulty producing speech sounds or producing sounds in the correct order. Depression and anxiety affect 70% of left brain stroke victims, and may inhibit effective rehabilitation or cause patients to regress in their recovery.

Nonspecific Effects

Victims of right and left brain strokes may also suffer from difficulties with verbal memory. They are unable to retain what had been communicated to them verbally and might completely forget what had been said to them immediately beforehand. Simple math skills can also be lost. "Among stroke survivors, about 40% have moderate functional impairment six months later, while about 10% to 15% remain severely disabled."⁵

RISK FACTORS

Certain personal behaviors and health conditions can lead to stroke if not addressed by affected individuals or their health care practitioners. These behaviors and conditions are

⁵ Andrew M. Kramer et al., "Outcomes and Costs after Hip Fracture and Stroke: A Comparison of Rehabilitation Settings," JAMA 277 (1997): 396. jama.ama-assn.org/cgi/content/abstract/277/5/396

commonly referred to as risk factors. It was only in the past 20 to 25 years that health came to be viewed as the comprehensive consequence of personal behaviors, permitting systematic study of health risks and behaviors as a basis for public health policy decisions. Smoking, overweight, or uncontrolled hypertension can lead to harmful outcomes, especially when existing simultaneously. Medical intervention is necessary to ameliorate some risk factors, as in cases of hypertension or diabetes. For many, improved diet, regular physical activity and smoking cessation can help prevent strokes. The Framingham Heart Study showed that the presence of certain risks, namely high blood pressure, diabetes, smoking and atrial fibrillation, together increase the likelihood of stroke in men and women over age 55 by 15% and 20%, respectively, over a ten-year period. Many risk factors linked to stroke are not controllable, however, such as race, age, sex, and genetic characteristics.

Culturally distinct populations may experience risk factors disproportionately. To gauge the public health risks associated with personal behaviors, the National Center for Chronic Disease Prevention and Health Promotion of the CDC established Behavioral Risk Factor Surveillance System (BRFSS) in 1984. The most recent 2004 BRFSS report is included below:

Risk Factors for Cardiovascular Disease	US	DE
Ever been told had high blood pressure	24.8%	27.7%
Ever been told had high blood cholesterol	33.1%	34.7%
Current Smoker	22.0%	21.9%
People reporting a diagnosis of diabetes	7.1%	7.7%
No leisure time physical activity	23.1%	26.5%
Adults who reported being overweight	36.8%	36.2%
Adults who reported not eating five fruits and vegetables per day	77.6%	78.0%
<i>Source: BRFSS, 2004</i>		

- TIAs carry a substantial short-term risk of stroke, hospitalization for cardiovascular events and death. Of 1,707 TIA patients evaluated in the emergency department (ED) of a large health care plan, 180 patients, or 10 percent, developed stroke within 90 days. Ninety-one patients, or 5 percent, did so within two days. Predictors of stroke: more than 60 years of age, having diabetes mellitus, focal symptoms of weakness or speech impairment, and TIA lasting longer than 10 minutes.
- The relative risk of stroke in heavy smokers (more than 40 cigarettes a day) is twice that of light smokers (less than 10 cigarettes per day). Stroke risk decreases significantly after two years and is at the level of nonsmokers by five years after cessation of cigarette smoking.
- Atrial fibrillation (AF) is an independent risk factor for stroke, increasing risk about five-fold.
- In adults over 55, the lifetime risk for stroke is greater than one in six. Women have a higher risk than men, perhaps due to their survival advantage.

- Blood pressure (BP) is a powerful determinant of stroke risk. Subjects with BP less than 120/80 mm Hg have about half the lifetime risk of stroke, compared to subjects with hypertension.
- Data from the GCNKSS study shows that ischemic stroke survivors with diabetes are younger, more likely to be African American, and more likely to have hypertension, myocardial infarction, and high cholesterol than nondiabetic patients.
- Pregnancy and Stroke
The Baltimore-Washington Cooperative Young Stroke Study found the risk of ischemic stroke or intracerebral hemorrhage during pregnancy and the first six weeks postpartum was 2.4 times greater than for non-pregnant women of similar age and race.
- Age
Because so many risk factors are chronic and cumulative, their consequences tend to increase over time; consequently, individuals face a sharply increasing risk from stroke as they age.

TREATMENT AND REHABILITATION OPTIONS

Treatment for Ischemic Stroke

Recent discussions about acute care therapies have been dominated by the advent of tissue plasminogen activator (tPA), the only clot dissolving agent currently approved for treatment of stroke by the FDA. This medication is administered intravenously to ischemic stroke survivors to break up blood clots that are interrupting blood flow to the brain. However, its use may cause hemorrhaging, which is likely to be fatal if the medication is administered to a hemorrhagic stroke patient misdiagnosed as ischemic. TPA and other thrombolytic treatments have a brief window of usefulness. Currently, they must be administered within three hours of the onset of symptoms, and particular patients must have favorable medical characteristics in order for them to be used safely and effectively.

Treatments other than thrombolytics may be administered as acute care therapy to stroke survivors. Anticoagulants and antiplatelet agents, which are used to prevent ischemic strokes, can also be used once a stroke occurs. They can aid in preventing further clotting, curtailing the growth of existing clots, and helping blood flow more freely through existing blockages. Aspirin can also be used as an antiplatelet therapy in the treatment of ischemic strokes. Other treatments include emergency carotid endarterectomy and carotid angioplasty. Both interventions can remove or clear blockages. Carotid endarterectomy is a procedure whereby plaque lining the interior of the carotid artery is surgically removed to allow for increased blood flow. Carotid angioplasty may also be used to increase blood flow by the insertion of a balloon tipped catheter into the carotid artery. The balloon is inflated to widen the artery and then removed.

Neuroprotective agents may be administered as treatment for ischemic stroke. These include calcium channel blockers and free radical scavengers. Calcium channel blockers prevent the potentially damaging flood of calcium into the brain that occurs in an ischemic stroke. Free radical scavengers bond with free radicals, which are unstable and damaging oxygen

compounds, to prevent them from causing brain damage. Ongoing studies are investigating the efficacy of neuroprotective agents for treating both ischemic and hemorrhagic strokes.

As we shall see in the chapter on acute care recommendations, stroke treatment professionals are concerned that many hospitals lack adequate resources to properly use tPA and other thrombolytics. First and foremost, a computed tomography (CT) or a magnetic resonance imaging (MRI) device and trained medical staff must be available at all times.

Treatment for Hemorrhagic Stroke

Because of their different causes, hemorrhagic strokes are treated differently from ischemic strokes. Doctors employ several methods to treat subarachnoid and intracerebral hemorrhages. An aneurysm is clipped or coiled to prevent rebleeding or rupturing. Medications are administered to prevent or treat spasms that may constrict the blood vessels. Also, stool softeners and cough suppressants can be used to reduce the risk of straining. If there is excessive cerebrospinal fluid in the brain's ventricles it may be drained via surgical procedure. In the case of intracerebral hemorrhage, emergency surgery may involve draining a hematoma, or pool of blood, that is exerting pressure on the brain. Treatments for ischemic stroke and seizures may be needed if those conditions are present as well.

REHABILITATION: Team Approach

Rehabilitation after a stroke is a comprehensive process that involves physical, cognitive, and speech therapies and counseling. Therapists, counselors, and other health providers are coordinated to enable the victim to regain as much of her normal life as is possible. A typical rehabilitation team is led by a physiatrist or other appropriate physician, and may include a neuropsychologist, psychologist, speech, physical, occupational, respiratory and recreational therapist, clinical dietician, nurse, vocational counselor, and the patient's caregiver. Each plays an important and integral role in the management of each patient's rehabilitation.

One of the most important members of the rehabilitation team is the survivor's caregiver. This person may be the spouse, relative, friend, or employee who takes on the role of providing round the clock home care. Most family members have no formal training in stroke rehabilitation, yet they are often thrust to the center of the rehabilitation plan. It is important that these caregivers receive the support of rehabilitation professionals and other family and friends in order for the survivor to achieve the fullest possible recovery.

A wide range of resources are available to the family caregiver for help and support. These resources not only help with the survivor's rehabilitation but are also important in helping the caregiver with his or her new role in life on a personal level. In fact, the survivor's success in rehabilitation is often closely related to how well the family caregiver can cope with that role.

To efficiently use the type of care that targets a stroke victim's rehabilitative needs, the factors to consider include the patient's physical condition and the family's ability to assist care. Placement alternatives include rehabilitative hospitals, units with a dedicated brain injury program, skilled nursing homes, intermediate nursing homes, sub-acute nursing homes, assisted living, and outpatient treatment with intermittent therapeutic visits to a patient's home.

Medicare reimbursement standards provide coverage for at least three hours of therapy daily, five days per week. Under Medicare guidelines, this is the minimum amount of rehabilitation services that a patient needs to justify an acute inpatient rehabilitation admission.⁶

While there are no rules and no one piece of scientific data that can predict success, the following seven factors can help the rehabilitation team assess the chances for recovery:

1. A quick, spontaneous return of some voluntary muscle movement
2. No severe visual or sensory loss
3. An ability to resume swallowing and eating soon after one's stroke
4. Intact cognitive ability to follow instructions
5. Bladder and bowel continence
6. Treatable depression
7. Supportive family and friends.⁷

There are six goals that should be attained by rehabilitation therapy teams.

The first goal is to continuously evaluate the patient and his progress. Conditions and needs are fluid and change frequently. The plan must reflect the current needs, what is attainable in terms of progress, and how it will be achieved.

The second goal is to avoid or minimize complications at all costs. Conditions that are a danger to the patient and his recovery must be monitored and treated, if not prevented entirely.

The third goal is to provide a structured, consistent, and secure environment.

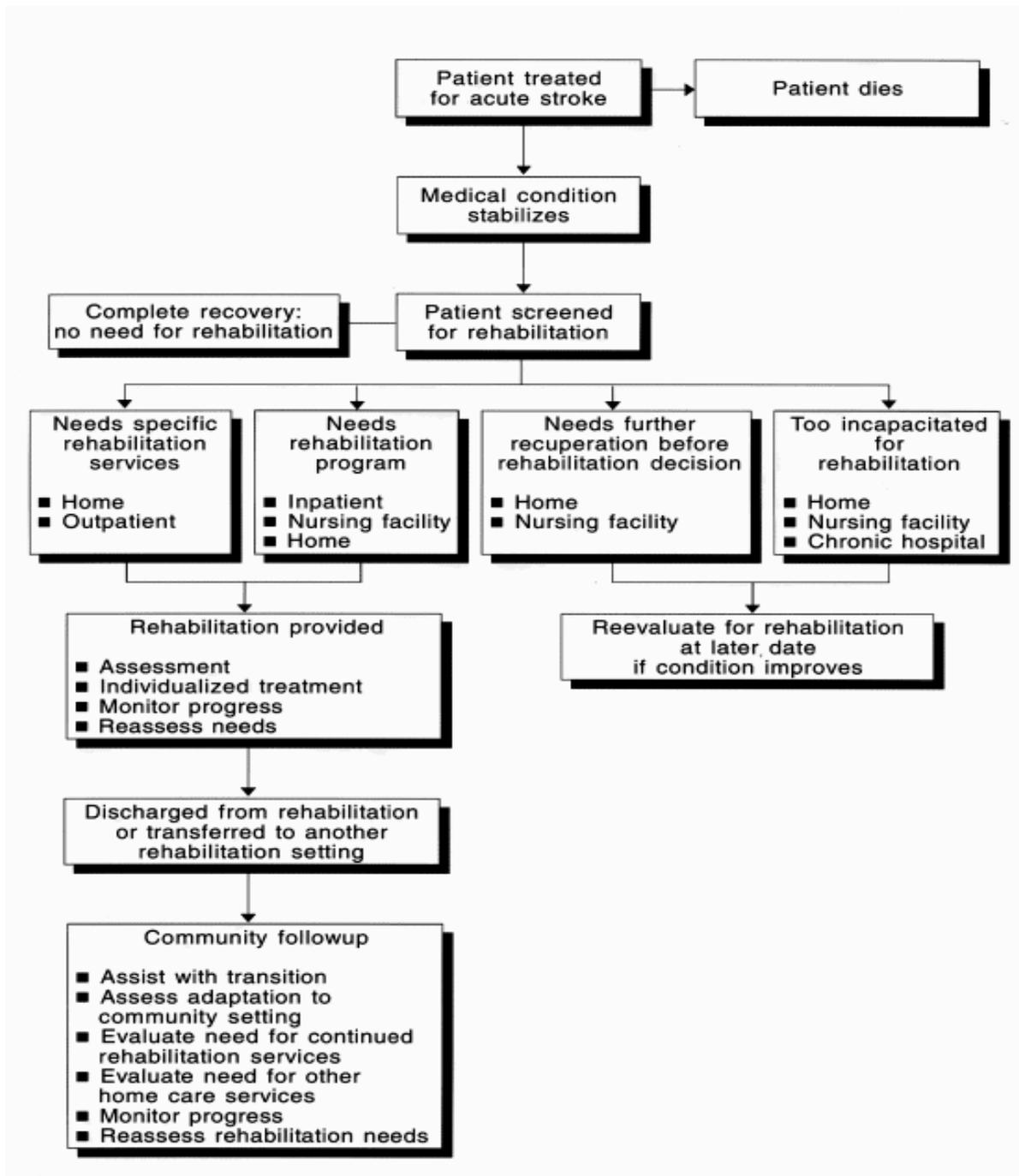
Fourth, the therapy team must teach compensatory skills. If the patient is unable to perform routine but necessary tasks, the therapy team must provide him with the knowledge, flexibility, and means by which disabilities can be overcome.

The fifth goal is for the team to build the morale of the patient and encourage him to learn and use the coping methods he is taught. The final goal is to have the patient be able to live as normally and independently as possible in surmounting the new challenges of everyday life.

⁶ (CMS, http://cms.hhs.gov/manuals/10_hospital/ho00.asp November 8, 2002)

⁷ Living with Stroke: A Guide for Families, Author: Dr. Richard Senelick, Neurologist ISBN #1891525107, Publisher: HealthSouth Corporation, copyright 2001

Diagram 1: Clinical Flow Diagram For Stroke Rehabilitation, Source: NIH⁸



⁸ <http://www.ncbi.nlm.nih.gov/books/bv.fcgi?rid=hstat6.section.28941>

STROKE ORGANIZATIONS

This section identifies programs and initiatives aimed specifically at the prevention and treatment of stroke that are currently available to the public. Based on the key participating organizations, each program is summarized and classified as professional, public and volunteer, or government.

PROFESSIONAL

National Stroke Project

The main objective of this project is to decrease the morbidity and mortality rate related to stroke by improving the quality of care.⁹ It was created as a quality improvement organization program, funded by CMS. The program is carried out by a national network of private organizations to promote the adoption of antithrombotics and other stroke therapies, increase appropriate diagnostic testing, and educate patients and their families and caregivers.

PUBLIC AND VOLUNTEER

American Stroke Association (ASA)

The American Stroke Association is a division of the American Heart Association (AHA) that focuses on reducing risk, disability and death from stroke through research, education, fund raising and advocacy. The American Heart Association created the American Stroke Association after many years of increasing emphasis on stroke. AHA/ASA spends more money on stroke research and programs than any other organization except the federal government.

An alliance with the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) culminated with the launch (in February 2004) of a voluntary [Primary Stroke Center Certification Program](#), allowing consumers and EMS professionals to identify those hospitals equipped to treat acute stroke according to nationally-recognized standards. The relationship also drives the first potential set of nationally recognized performance measures into testing. In addition, AHA/ASA has launched a major quality improvement program in the hospital setting called [Get With The Guidelines/Stroke](#) to provide tools for physicians to care for stroke survivors according to our scientific guidelines.¹⁰

An example of the collaborative nature of the American Heart Association and American Stroke Association is a strategic alliance with the Centers for Disease Control; the National Heart, Lung, and Blood Institute; and the National Institute of Neurological Disorders and Stroke. Together, these organizations coordinate efforts on a national level to support the overarching goals of the United States Surgeon General's Healthy People 2010 program.

ASA has designated May as Stroke Awareness Month. During this month, organizations are especially encouraged to use media campaigns to enhance public awareness of stroke warning signs and risk reduction strategies and to perform risk assessment screenings through the Stroke Alert risk assessments program. Particularly during May, ASA publicizes its toll-free number, which the public may call to find the nearest risk assessment site.

⁹ HCFA, "Stroke National Project Overview," "Medicare Priorities," HCFA Pub. no.10156, version 5.2 (2000), 23.

¹⁰ www.strokeassociation.org

National Stroke Association (NSA)

The mission of NSA is to reduce the incidence and impact of a stroke.

The organization devotes its entire resources to stroke, providing an extensive range of programs that concentrate on all stages of stroke. NSA's prevention programs and guidelines offer screening tools and prevention educational materials about stroke symptoms. Public Health Outreach allows NSA to partner with state and local public health departments to spread prevention messages. Furthermore, its Ethnic Disparities Initiative focuses attention and educational campaigns on minority populations. NSA's Acute Treatment Program assists hospitals through personal consultations and specific recommendations to provide the best stroke care possible.

National Stroke Council (NSC)

The National Stroke Council, a program of the National Emergency Medical Association (NEMA), supports research and education on the causes

GOVERNMENT—FEDERAL

Department of Health and Human Services (HHS)

Healthy People 2010 presents a comprehensive health promotion and disease prevention agenda. Developed by HHS, its two overarching goals are to increase quality and years of healthy life and to eliminate health disparities among ethnic groups. The plan states 28 focus areas, stating a goal for each area. Within each focus area a list of objectives is prescribed; a total of 467 such objectives are propounded for the nation.

In this plan, stroke is included in the focus area of cardiovascular disease. The goals for this focus area are "improve cardiovascular health and quality of life through the prevention, detection, and treatment of risk factors; early identification and treatment of heart attacks and strokes; and prevention of recurrent cardiovascular events." Two specific objectives are identified for stroke:

1. Reduce the stroke death rate by 20%
2. (Developmental) Increase the proportion of adults who are aware of the early warning symptoms and signs of a stroke.

National Institute of Neurological Disorders and Stroke (NINDS)

NINDS is a division of the National Institutes of Health established to conduct and support research, training, health information dissemination and other programs with respect to neurological diseases and disorders and stroke. NINDS developed the Know Stroke education campaign to inform the public of the symptoms of stroke and the importance of getting to the hospital quickly. The program can be set up and shown in a variety of settings including hospitals, senior citizen centers, health clinics and fairs, and community and church meetings.

DELAWARE

Delaware Stroke Initiative

<http://www.udel.edu/destroke/index.html>

The mission of the **Delaware Stroke Initiative** (DSI) is to improve stroke prevention, risk assessment, and recovery to residents of the state of Delaware with special focus on low income and minority individuals.

Delaware Health Care Commission

<http://www.state.de.us/dhcc/aboutagency.shtml>

The Delaware General Assembly created the Delaware Health Care Commission in June of 1990 to develop a pathway to basic, affordable health care for all Delawareans.

The Delaware Health Care Commission embodies the public/private efforts which have traditionally spelled success for problem solving in Delaware. Four government officials - the Secretary of Finance, Secretary of Health & Social Services, Secretary of Children, Youth & Their Families and the Insurance Commissioner - are joined by six private citizens appointed either by the Governor, the Speaker of the House or the President Pro Tempore of the Senate. The composition is a balance between the executive and legislative branches of government and the public and private sectors.

By creating the Commission as a policy-setting body the General Assembly gave it a unique position in state government. It is intended to allow creative thinking outside the usual confines of conducting day-to-day state business. The Commission is expressly authorized to conduct pilot projects to test methods for catalyzing private-sector activities that will help the state meet its health care needs. To achieve its goals, the Commission strives to balance various viewpoints and perspectives.

The Commission generally has followed a strategy built on the notion that initial efforts should target areas most in need and gradually build toward a more comprehensive plan. Since 1995, the Commission has used a committee system as a means of reaching out to the community and involving those impacted by its decisions in the consensus building process.

Delaware Division of Public Health

<http://www.dhss.delaware.gov/dhss/dph/index.html>

The Division of Public Health's mission is to protect and enhance the health of the people of Delaware by: Working together with others; Addressing issues that affect the health of Delawareans; Keeping track of the state's health; Promoting positive lifestyles; Responding to critical health issues and disasters; Promoting the availability of health services. The organization is divided into eleven sections, including several that are critical to the work of the Stroke Task Force, including:

- Division of Public Health
- Center for Health Information & Science: Bureau of Chronic Diseases
- DE Health Statistics
- Emergency Medical Services
- Long Term Care Facilities
- Health Systems Management

Stroke Office: Macro Perspective

Because the impact of stroke on Delaware is demographically more serious than in most other states, Delaware should consider an aggressively proactive approach. Accordingly, the task force recommends that Delaware enact legislation creating a stroke office to lead our public health response. The office should be guided by an interdisciplinary stroke council, including essential public and private stakeholders, while ensuring participation by stakeholders not directly represented on the council.

Maryland, Ohio, and Mississippi have similar offices, which are administered through the respective health departments, but are not directed by the departments. As the Ohio Council on Stroke Prevention and Education deals exclusively with stroke, it could readily serve as a model for a Delaware stroke office. As the Maryland and Mississippi legislation indicates, a significant alternative is an office that combines stroke responsibilities with cardiovascular disease (CVD), which is the leading cause of death in the United States and in Delaware. This option has the advantage that the risk factors for CVD and stroke are largely identical, so that a combined office could deal with both without duplication. On the other hand, the advisory committee has expressed concern that where an organization combines services for CVD and stroke, stroke tends to receive a much lower priority.

ADMINISTRATIVE APPROACHES

If STOP or similar legislation is enacted by Congress, establishment of a stroke office will give Delaware a head start toward qualifying for funding there under and a vehicle for the well-coordinated and effective use of available resources. In order to be effective, the office must be afforded adequate public and private resources to perform its duties. Through the stroke office, Delaware can allocate the tasks in light of available resources over time in accordance with well-considered priorities.

PREVENTION RECOMMENDATIONS FOR UNDERSERVED POPULATIONS

Prevention initiatives must address the specific requirements of underserved urban and rural populations. All prevention initiatives, especially those directed at education and behavior change must acknowledge and be responsive to the unique cultural norms of the public intended to be served. It is also important that there be a careful review of existing public and private programs to avoid duplication of efforts. As with other phases of stroke response, the stroke office would support existing efforts to provide resources to local consortia where these exist and direct assistance to specific organizations where regional coordination is less advanced.

REDUCING RISK FACTORS, MORBIDITY AND MORTALITY

The United States Constitution is based on respect for individual liberties that places a large part of the responsibility for maintaining public health on individual citizens. Active public health education initiatives can increase public awareness of personal measures that reduce the risk of stroke. In recognition of this, the STOP legislation provides for a national education and information campaign to promote stroke prevention and increase the number of patients who seek immediate treatment. The stroke office should give high priority to the encouragement and establishment of educational programs to raise health care provider and

public awareness about risk factors for stroke, particularly hypertension, diabetes, smoking, high cholesterol, and obesity.

People are unable to detect hypertension, high cholesterol, and diabetes without diagnostic tests. Therefore, screening and diagnosis of those conditions must be emphasized; early recognition of risk factors increases the effectiveness of preventive intervention. Resources should be allocated to encourage education of patients and their families in pre-hospital and hospital care. Equally important is broad public education aimed at publicizing the warning signs of stroke and the necessity of contacting emergency personnel through the 9-1-1 system as soon as these symptoms appear.

As mentioned, educational programs must be culturally appropriate to Delaware's diverse ethnic and racial makeup. This report advocates that educational programs and materials be written in both Spanish and English, use colorful illustrations and non-technical terms, use group presentations and public service announcements on multi-cultural radio and television stations, and acknowledge cultural differences within the community. Attention to these factors may improve the effectiveness of outreach programs among African Americans, Asian Americans, and recent immigrants, as well as Hispanic Americans. Moreover, educational materials should be made accessible to as many demographic groups as possible by means of assistive technology and other accommodations to the disabled, illiterate, and senior populations.

The number of strokes that occur while patients are being treated for other conditions is cause for concern. A multidisciplinary rapid response protocol should be developed to reduce the risk of suffering a stroke in this situation as well as to improve acute care should such a stroke occur. The protocols should help educate emergency, pre-hospital, and hospital personnel about stroke risks while in care and coordinate responses to this danger.

ACCESS TO BEST PREVENTIVE PRACTICES

The stroke office should establish a system to collect and disseminate best practices for preventive care, using the best available expertise of health care practitioners. Included in preventive best practices should be guidelines for disease management of associated conditions, particularly diabetes, hypertension, elevated cholesterol, and obesity.

Patients may not access preventive care due to cost considerations. Therefore, the stroke office should conduct a study of the adequacy of current insurance coverage for diagnostic services and preventive care, especially for at-risk populations.

Voluntary upgrades in coverage may be encouraged by state-supported research showing that it is cost-effective to provide preventive coverage. The stroke office may assist this by designating five or six preventive measures as subjects for a cost effectiveness study; these measures may include blood sugar and blood pressure screening and treatment.

RESEARCH AND INFORMATION: Clearinghouse and Registry

A stroke information clearinghouse should be established in order to coordinate the dissemination of stroke research and information. The clearinghouse can provide information for medical practitioners, researchers, public health organizations, and the public. It can provide background information for educational programs that address all sectors regarding

aspects of stroke prevention. It can also collect stroke prevention research and coordinate information from state data collection agencies, third party payers, and others to help target the most effective use of resources. For example, the clearinghouse could gather clinical research, such as that currently being conducted by NINDS on basic neurology, use of warning signs to prevent stroke, and a possible vaccine for stroke.¹¹

The Stroke Task Force recommended exploration and dialogue with the Provost and appropriate departments at the University of Delaware about the possibility of collaborating on the development of a rehabilitation research and treatment center at the University, dedicated to stroke and brain injury. Although stroke-related rehabilitation research is taking place at a number of sites throughout the country, it often takes a substantial amount of time for the results of such research to filter down to therapists and to effect patient care. Of course, this limitation would not be eliminated by establishing a rehabilitation/research center in Delaware. However, a state-of-the-art, combined research and treatment center in the state of Delaware would allow for appropriate patients to receive rehabilitation care while at the same time participating in the development of novel treatment approaches, as well as enhancing the possibility of increased funding for efforts to advance stroke rehabilitation in the state. This possibility already exists on a limited basis as several faculty members at the University of Delaware are engaged currently in a variety of federally funded studies on stroke rehabilitation. The limited existing rehabilitation centers located in Delaware are unlikely to make such research a priority given their financial and personnel constraints. The University of Delaware is in a unique position to take on this endeavor given that a physical therapy department already exists on campus and it is already engaged in rehabilitation research. There is also discussion underway for establishing a speech therapy program at the university. Support for such a center could be part of a broader State plan to obtain funding through the proposed Stop Stroke Act when those monies become available. A dedicated rehabilitation research and treatment facility would provide a mechanism to foster ongoing and future research and provide the possibility for faster dissemination of new treatment methods to therapists in Delaware and, subsequently, to stroke survivors.

A stroke registry should be established in order to assist medical research into stroke treatment and prevention. A registry is a medical database on persons treated for a specific condition, collected in such a manner that the confidentiality of individual patients is preserved. The stroke office, in collaboration with the stroke information clearinghouse, could determine how best to take advantage of the Paul Coverdell National Acute Stroke Registry¹² and guide efforts to collect additional information in Delaware.

It is especially vital that population-based research be conducted to improve the effectiveness of educational programs, especially targeting populations that are underserved because of geographic, socioeconomic, or cultural factors. The data should be used to develop an array of approaches to address specific audiences in a culturally appropriate manner. Included in the population-based research should be continuous analysis of outcomes, including the monitoring of behavioral changes. Among the issues that should be addressed is the extent to which lack of insurance coverage, especially for uninsured and underinsured Delawareans, may affect medical care for stroke and its precursor conditions.

¹¹ See NINDS, "2002 Stroke Testimony" http://www.ninds.nih.gov/about_ninds/2002_stroke_testimony.htm (June 11, 2002).

¹² CDC: Programs in Brief: Chronic Disease Presentation, www.cdc.gov/programs/chron07.htm

ACUTE CARE GOAL: One-Hour Away

Delaware should establish as a goal that no Delaware resident should be more than one hour away from a hospital with the capability of treating all acute strokes. This is a demanding goal, but it follows from the fact that there is only a limited time period—often as little as three hours—from the onset of stroke symptoms to irreversible damage due to death of brain cells. If a patient calls EMS one hour after onset of symptoms and EMS transports the patient to the hospital in 30 minutes, the medical staff at the hospital may have only 1-1/2 hours to evaluate the patient and commence thrombolytic or other indicated therapy. Within this time frame the hospital must confirm the diagnosis of stroke, notify relevant hospital staff, take a patient history, perform a physical exam (including diagnostic tests and blood work), perform and analyze a noncontrast CT scan, evaluate the tests and blood work, and prepare the patient for administration of the treatment (such as starting intravenous lines).¹³

STROKE RESPONSE PLAN: Appropriate Dispatch

To mobilize the public health system of Delaware to maximize responsiveness, it is evident that a comprehensive stroke response plan will be necessary. The stroke office should conduct an inventory of all hospitals in the State of Delaware to assess whether all the resources necessary for hospitals to initiate effective stroke treatment are available and accessible to all residents within one hour's time, ideally. The inventory can be used to help hospitals obtain the necessary resources to meet that level of capability.

Based on this inventory, the Stroke Office and EMS may make recommendations to accomplish the one-hour access goal, with input from the broad spectrum of stakeholders.

TREATMENT STRUCTURE: Treat or Divert

While tPA can be beneficial in treating a large proportion of ischemic strokes, only a small percentage currently receive it. In response to the underutilization of tPA and other stroke therapies, the Brain Attack Coalition (BAC) has developed criteria to facilitate maximum utilization of the drug, taking into account that it must be administered quickly but is strongly contraindicated for patients with hemorrhagic stroke. BAC criteria set forth standards for eleven major aspects of stroke care: acute stroke teams, written care protocols, emergency medical services, emergency department, stroke unit, neurological services, commitment and support of the medical organization, neuroimaging, laboratory services, outcomes and quality improvement, and educational programs.

The BAC criteria for neurological services are quite stringent. *"Primary stroke centers must have the capability of performing either a cranial computed tomographic scan or a brain magnetic resonance imaging scan within 25 minutes of the order being written. These imaging capabilities must be available 24 hours everyday."*¹⁴ Access to professional evaluation of neuroimaging can be facilitated by the use of telemedicine technology, which allows internet transmission of a patient's CT and MRI images to a qualified specialist.

¹³ Joel Leon Telles and Kimberly Greene, "Protocol Design and Improving Acute Stroke Care," DVHC, 2001, 11-13. www.dvhc.org/downloads/Protocol_Design_and_Improving_Acute_Stroke_Care.pdf

¹⁴ Mark J. Alberts et al., "Recommendations for the Establishment of Primary Stroke Centers," *JAMA* 283 (2000): 3102–3109. jama.ama-assn.org/cgi/content/abstract/283/23/3102

PROMOTING IMPROVED CARE

The stroke office should inventory the capability of all Delaware acute care hospitals to diagnose and initiate treatment for acute stroke.

Where gaps exist, the stroke office should recommend a plan to develop that capability for all Delaware locations. Hospitals that wish to develop a more comprehensive approach to the treatment of stroke should refer to published criteria available in the medical literature and from stroke advocacy groups. The stroke office should ensure that information about those hospitals that have the capability to diagnose and treat acute strokes should be publicly available.

Acute care hospitals should designate as a quality indicator either compliance with BAC (or similar criteria certifying capability for treating all strokes) or entry into an arrangement for the transfer of appropriate patients to the nearest hospital capable of treating all acute strokes. In primary treatment centers, this structure would require each hospital to assess the patient's condition and decide whether to treat or transfer. The inventory and statewide stroke treatment system can help hospitals create their own arrangements by structuring the information flow regarding the capabilities of the providers. This stroke system would also reveal gaps in capability that need to be addressed.

Through the stroke office, Delaware would keep an official record of providers who self-designate or who undergo voluntary independent certification by an appropriate certifying organization. Delaware would then disseminate this information to EMS providers and other interested persons and organizations. Qualifying providers could then make known that they are self-designated or certified as stroke treatment centers.

The emphasis in acute care policy at this time should be on providing high-quality stroke care at all acute care hospitals.

Rehabilitation Recommendations: CONTINUITY OF CARE

More than almost any other medical condition, stroke raises problems of continuity of care, because care may be provided to patients disabled by the disease over a long period of time in a variety of possible settings. Promoting continuity of care will help insure that effective rehabilitative services are provided in a consistent and timely manner.

The first decisions that may crucially affect the success of rehabilitation typically occur in the acute care hospital during the discharge planning for the stroke victim. Early intervention by rehabilitative professionals will often result in better outcomes. A psychiatrist or other appropriately trained professional should be involved upon the initiation of treatment in the acute care facility to help formulate the treatment plan and to guide the selection of the best site for continued care, thereby helping to assure better continuity in the transition from acute care. Once a stroke patient is placed in a rehabilitative facility, a facility based professional case manager should coordinate the therapists and nurses to assure continuity of care and achieve an effective team approach. Rehabilitation planning must include the patient's caregiver as a member of the team.

Through the stroke office, a consensus statement of best practices for assuring continuity of care should be adopted or, if necessary, developed, based on guidelines informed by leading research initiatives. To provide scientific evidence to promote informed clinical policy in

rehabilitation, such studies must evaluate rehabilitative outcomes, advance measurement of outcomes, and evaluate emerging therapies and technologies.

ACCESS TO APPROPRIATE CARE

In the opinion of advisory committee members, stroke victims are often placed in care that does not afford them the maximum opportunity to regain functional independence. It seems that many patients are assigned to nursing homes who could have returned home if they had been given intensive rehabilitation as soon as the patient could tolerate it. A study comparing assignment of stroke survivors after hospitalization found that Medicare HMO patients were more likely to be discharged to nursing homes than fee-for-service patients, although mortality rates were not significantly different.¹⁵ In order to determine the extent to which this is the case, the stroke office should study the use of the different placement alternatives for stroke rehabilitation. The state of knowledge concerning the most effective attributes of rehabilitative therapy is currently inadequate for clinical or policy purposes.¹⁶

Health professionals should ensure that patient caregivers are afforded all possible support, including information and other assistance needed to obtain help from public agencies and community-based services.

EVIDENCE-BASED STANDARDS FOR REHABILITATION PLANS

The stroke office should promote awareness of evidence-based rehabilitation guidelines and protocols established by professional organizations. Guidelines are being developed by the Office of Research and Development of the federal Department of Veterans Affairs and other public and private officials. These guidelines provide specific directives on medical management, patient assessment, referral, rehabilitation management, and reintegration into the community.¹⁷

The proposed Stroke Office would be responsible for researching existing evidence-based rehabilitation guidelines and protocols as well as actively pursue emerging best practices.

STANDARDS FOR UNACCREDITED FACILITIES

The subcommittee discussed the need to ensure that facilities providing services are complying with quality standards and services and are subject to appropriate industry and professional standards. In the experience of advisory committee members, stroke survivors are often limited by insurance carriers to receive rehabilitative therapy from providers that either lack adequate facilities or lack individuals with specialty certification for treating individuals with neurological impairments, or both. Private insurers should contract only with facilities and providers that are either licensed in Delaware to provide rehabilitative services or nationally accredited for the contracted services.

¹⁵ Sheldon M. Retchin, M.D. et al., "Outcomes of Stroke Patients in Medicare Fee for Service and Managed Care," *JAMA* 278 (1997): 119-24. jama.ama-assn.org/cgi/content/abstract/278/2/119

¹⁶ Kramer, "Outcomes and Costs," 403. jama.ama-assn.org/cgi/content/abstract/277/5/396

¹⁷ <http://stroke.ahajournals.org/cgi/content/full/strokeaha;31/4/1002>

FUNDING SOURCES

PROPOSED STOP ACT

The Stroke Treatment and Ongoing Prevention (STOP) Act of 2002¹⁸ has been introduced in Congress to create a program to lead the nation's fight against stroke. The goal of this legislation is to improve care of stroke victims throughout the nation (§ 2(b)).¹⁹ If enacted, HHS would be directed to create a campaign aimed at promoting prevention of stroke and increasing the number of stroke victims who seek treatment immediately; this national educational and informational campaign is authorized to be appropriated \$40 million for fiscal year 2002. (§ 2801). HHS would institute a grant program to enable states to develop care systems for stroke and provide technical assistance to the grantees (§ 2811). It would also expand the Paul Coverdell National Acute Stroke Registry and Clearinghouse and ensure the availability of published research on stroke or research prevention, diagnosis, treatment, and rehabilitation of stroke. The department would be authorized to study all phases of care and grant funds to public and private non-profit corporations (§ 2812). HHS would grant funds to states to establish statewide stroke prevention, treatment, and rehabilitation systems (§ 2821(a)). Each grantee would oversee and implement a statewide system to train emergency medical services, ensure access to care of a standardized quality, and support facilities with smaller numbers of patients (§ 2821(b)).

To receive a grant, a state would be required to match federal funds with non-federal contributions and adopt standards of care for stroke victims.

After the first year the state's responsibility to match funds is phased in from a 1:3 state to federal ratio to an even match (§§ 2821(a), 2822, and 2823(c)). In adopting standards, a state must consider national standards, with the primary goal being the highest quality of care (§ 2823(c)). The authorization of appropriations for this program would be \$50 million for fiscal year 2002, increasing to \$125 million for fiscal year 2006. No more than 10% of a state's grant could be spent on administrative expenses (§ 2830).

CDC's Chronic Disease Prevention and Health Promotion Programs²⁰

In collaboration with public and private health organizations, CDC has established a national framework to help states obtain the information, resources, surveillance data, and funding needed to implement effective chronic disease prevention programs and ensure that all Americans have access to quality health care. CDC funding and support enable state health departments to respond efficiently to changing health priorities and effectively use limited resources to meet a wide range of health needs among specific populations. The table, located on page 37, is their most recent breakdown of the CDC's 2003 Fiscal Year funding awards to Delaware in the areas of cancer, heart disease, stroke, and related risk factors, as available through their web site on October 25, 2006.

In addition, Delaware Division of Public Health, Bureau of Chronic Disease has provided more recent and complete 2006-07 Fiscal Year information regarding Delaware's specific programs on page 38 of this report.

¹⁸ S.1274, 107th Congress (2002) [http://thomas.loc.gov/cgi-bin/cpquery/R?cp107:FLD010:@1\(sr097\)](http://thomas.loc.gov/cgi-bin/cpquery/R?cp107:FLD010:@1(sr097))

¹⁹ The substantive text of the proposed STOP Act is set forth in Section 3 of the legislation.

²⁰ <http://www.cdc.gov/nccdphp/publications/factsheets/ChronicDisease/delaware.htm> (Fiscal Year 2003 data)

CDC Cancer, Heart Disease, Stroke, and Related Risk Factor Funding for Delaware, FY 2003	
SURVEILLANCE	
Behavioral Risk Factor Surveillance System (BRFSS)	\$111,972
Delaware BRFSS	
National Program of Cancer Registries Delaware Cancer Registry	\$271,288
CHRONIC DISEASE PREVENTION AND CONTROL	
Cardiovascular Health Program	\$0
Diabetes Control Program	\$410,000
Delaware Diabetes Prevention and Control Program	
National Breast and Cervical Cancer Early Detection Program	\$834,138
Screening For Life	
National Comprehensive Cancer Control Program	\$125,000
Cancer Prevention and Control Program	
WISEWOMAN	\$0
MODIFYING RISK FACTORS	
National Tobacco Prevention and Control Program	\$794,493
Delaware Tobacco Prevention and Control Program	
State Nutrition and Physical Activity/Obesity Prevention Program	\$0
Racial and Ethnic Approaches to Community Health (REACH 2010)	\$0
Total	\$2,546,891
<i>The shaded area(s) represents program areas that are not currently funded. The above figures may contain funds that have been carried over from a previous fiscal year.</i>	

ADDITIONAL FUNDING SOURCES

Implementing these recommendations will require a substantial commitment of financial resources. In the present constrained fiscal environment, a variety of funding sources must be tapped to support a major initiative such as that outlined in this report, including creation of public-private partnerships. Another potential source of funding may be through special appropriated funds possibly made available through an increase in tobacco excise tax and/or a dedicated lottery. The Stroke Office would be responsible for seeking funding opportunities through appropriate foundations and medical charities. An immediate goal is to prepare Delaware's application for CDC funding, as described on page 8 of this report.

The Stroke Task Force believes that directing funds and efforts toward enhancing stroke prevention and care will produce a return on investment by helping more Delawareans achieve longer, healthier lives, free of the tragic effects of stroke that darken the lives of our citizens and families. In addition, Delaware's health care economic burden will be decreased in direct correlation with a decrease in stroke incidence.

Glossary of Terms

Acronym	Definition
AF	Atrial Fibrillation
AHA	American Heart Association
AHCPR	Former name of the Agency for Healthcare Research & Quality
AHRQ	U.S. Agency for Healthcare Research & Quality
ALOS	Average Length of Stay
AMPAC	Activity Measure for Post-acute Care
ASA	American Stroke Association
BAC	Brain Attack Coalition
BP	Blood Pressure
BRFSS	Behavioral Risk Factor Surveillance System
CDC	Centers for Disease Control & Prevention
CMS	Centers for Medicare & Medicaid Services
CQI	Continuous Quality Improvement
CT	Computed Tomography
CVD	Cardiovascular Disease
DEHA	Delaware Healthcare Association
DHCC	Delaware Health Care Commission
DHIN	Delaware Health Information Network
DHSS	Delaware Department of Health & Social Services
DPH	Division of Public Health (Division within DHSS)
DSI	Delaware Stroke Initiative
DVHC	Delaware Valley Healthcare Council (Healthcare Assoc. of PA)
ED/ER	Emergency Department / Emergency Room
EMD	Emergency Medical Dispatch
EMS	Emergency Medical Service
GCKSS	The Greater Cincinnati/Northern Kentucky Stroke Study
HCFA	Health Care Financing Administration (now known as CMS)
HHS	U.S. Dept. Health & Human Services
HMO	Health Maintenance Organization
ICF	International Classification of Function
JAMA	Journal of the American Medical Association
JCAHO	Joint Commission on Accreditation of Healthcare Organizations
MRI	Magnetic Resonance Imaging
NEJM	New England Journal of Medicine
NIH	National Institutes of Health
NINDS	National Institute of Neurological Disorders and Stroke
NSA	National Stroke Association
NSC	National Stroke Council
OB/GYN	Obstetrics/Gynecology
SNF	Skilled Nursing Facility
OEMS	Office of Emergency Medical Service (Section within DPH, DHSS)
STOP	Stroke Treatment and Ongoing Prevention (STOP) Act of 2002
TIA	Transient Ischemic Attack
tPA	Tissue Plasminogen Activator (drug treatment option)
VAHSR&D	Veterans Affairs Health Services Research and Development

APPENDICES

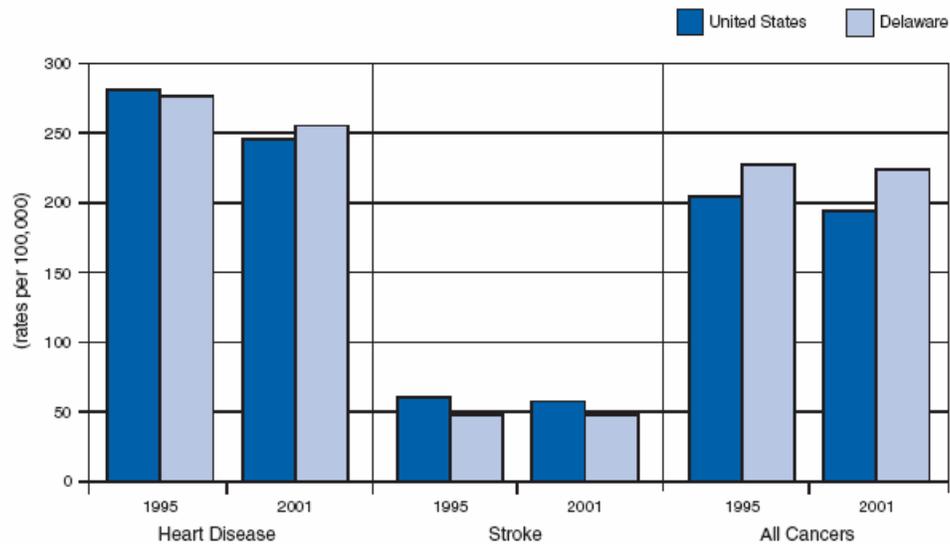
- Appendix 1:** CDC Chronic Diseases Leading Causes of Death: Delaware
- Appendix 2:** Sub-Committee Notes: Prevention & Primordial Care
- Appendix 3:** Sub-Committee Notes: Emergency Medical Services
- Appendix 4:** Sub-Committee Notes: Acute & Sub-Acute Care
- Appendix 5:** Sub-Committee Notes: Rehabilitation
- Appendix 6:** Sub-Committee Notes: Continuous Quality Improvement
- Appendix 7:** Ohio Plan to Prevent Heart Disease and Stroke Executive Summary
- Appendix 8:** Pennsylvania Proposed Stroke Office Legislation
- Appendix 9:** National Health Care Quality Report State Snapshot 2005
- Appendix 10:** Dr. Robert Rosenbaum Power Point Presentation
- Appendix 11:** Paul Silverman Power Point Presentation
- Appendix 12:** Steven Blessing Power Point Presentation
- Appendix 13:** American Heart Association 2006 Stroke At-a-Glance, published 12/2005



Chronic Diseases: The Leading Causes of Death

The Leading Causes of Death

United States and Delaware, 1995 and 2001



Source: National Center for Health Statistics, 2003

The Burden of Chronic Disease

Chronic diseases—such as heart disease, stroke, cancer, and diabetes—are among the most prevalent, costly, and preventable of all health problems. Seven of every ten Americans who die each year, or more than 1.7 million people, die of a chronic disease.

Reducing the Burden of Chronic Disease

Chronic diseases are not prevented by vaccines, nor do they just disappear. To a large degree, the major chronic disease killers are an extension of what people do, or not do, as they go about the business of daily living. Health-damaging behaviors—in particular, tobacco use, lack of physical activity, and poor nutrition—are major contributors to heart disease and cancer, our nation’s leading killers. However, tests are currently available that can detect breast cancer, colon cancer, heart disease, and other chronic diseases early, when they can be most effectively treated.

The Leading Causes of Death and Their Risk Factors

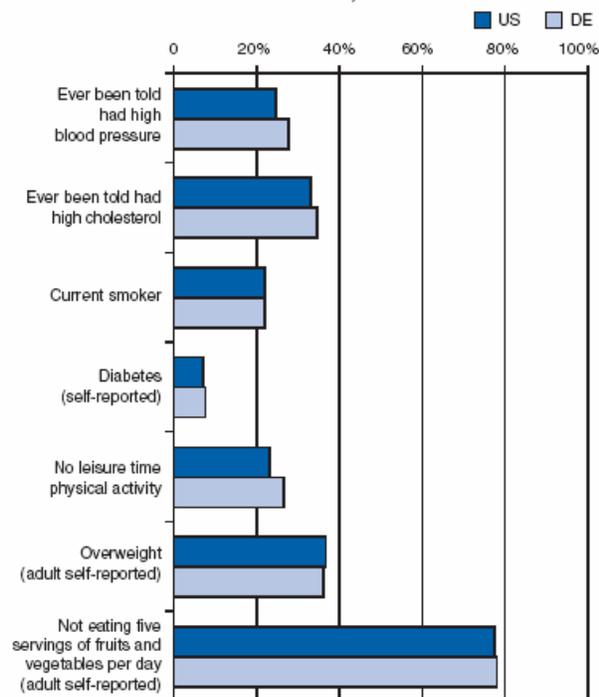
Heart Disease and Stroke

Heart disease and stroke are the first and third leading causes of death for both men and women in the United States. Heart disease is the leading cause of death in Delaware, accounting for 2,033 deaths or approximately 29% of the state's deaths in 2001 (the most recent year for which data are available). Stroke is the third leading cause of death, accounting for 383 deaths or approximately 5% of the state's deaths in 2001.

Prevention Opportunities

Two major independent risk factors for heart disease and stroke are high blood pressure and high blood cholesterol. Other important risk factors include diabetes, tobacco use, physical inactivity, poor nutrition, and being overweight or obese. A key strategy for addressing these risk factors is to educate the public and health care practitioners about the importance of prevention. All people should also partner with their health care providers to have their risk factor status assessed, monitored, and managed in accordance with national guidelines. People should also be educated about the signs and symptoms of heart attack and stroke and the importance of calling 911 quickly. Forty-seven percent of heart attack victims and about the same percentage of stroke victims die before emergency medical personnel arrive.

Risk Factors for Heart Disease and Stroke, 2003



Source: BRFSS, 2004

Cancer

Cancer is the second leading cause of death and is responsible for one of every four deaths in the United States. In 2004, over 560,000 Americans—or more than 1,500 people a day—will die of cancer. Of these annual cancer deaths, 1,810 are expected in Delaware. About 1.4 million new cases of cancer will be diagnosed nationally in 2004 alone. This figure includes 4,390 new cases that are likely to be diagnosed in Delaware.

Estimated Cancer Deaths, 2004

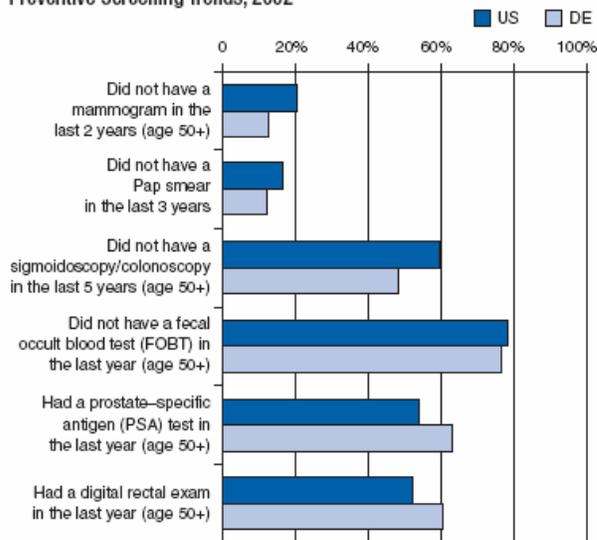
Cause of death	US	DE
All Cancers	563,700	1,810
Breast (female)	40,110	130
Colorectal	56,730	160
Lung and Bronchus	160,440	510
Prostate	29,900	90

Source: American Cancer Society, 2004

Prevention Opportunities

The number of new cancer cases can be reduced and many cancer deaths can be prevented. Adopting healthier lifestyles—for example, avoiding tobacco use, increasing physical activity, achieving a healthy weight, improving nutrition, and avoiding sun overexposure—can significantly reduce a person's risk for cancer. Making cancer screening, information, and referral services available and accessible is essential for reducing the high rates of cancer and cancer deaths. Screening tests for breast, cervical, and colorectal cancers reduce the number of deaths by detecting them early.

Preventive Screening Trends, 2002



Source: BRFSS, 2003

Delaware's Chronic Disease Program Accomplishments

Examples of Delaware's Prevention Successes

- Statistically significant decreases in cancer deaths for men across all races and for white women, with the greatest decrease occurring among African American men (496.1 per 100,000 in 1990 versus 292.2 per 100,000 in 2000).
- A 19.5% decrease in the number of women older than age 50 who reported not having had a mammogram in the last 2 years (from 32.3% in 1992 to 12.8% in 2002).
- A lower prevalence rate than the corresponding national rate for women older than age 18 who reported not having had a Pap smear in the last 3 years (12.1% in Delaware versus 16.7% nationally).

CDC's Chronic Disease Prevention and Health Promotion Programs

In collaboration with public and private health organizations, CDC has established a national framework to help states obtain the information, resources, surveillance data, and funding needed to implement effective chronic disease prevention programs and ensure that all Americans have access to quality health care. CDC funding and support enable state health departments to respond efficiently to changing health priorities and effectively use limited resources to meet a wide range of health needs among specific populations. The table below is a breakdown of the CDC's funding awards to Delaware in the areas of cancer, heart disease, stroke, and related risk factors.

CDC Cancer, Heart Disease, Stroke, and Related Risk Factor Funding for Delaware, FY 2003

SURVEILLANCE	
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Racial and Ethnic Approaches to Community Health (REACH 2010)	\$0
Total	\$2,546,891

The shaded area(s) represents program areas that are not currently funded. The above figures may contain funds that have been carried over from a previous fiscal year.

Additional Funding

CDC's National Center for Chronic Disease Prevention and Health Promotion funds additional programs in Delaware that fall into other health areas. A listing of these programs can be found at <http://www.cdc.gov/nccdphp/states/index.htm>.

Opportunities for Success

Chronic Disease Highlight: Diabetes

Diabetes, a serious disease requiring extensive medical monitoring and lifelong treatment, is a common cause of disability and death in Delaware. Data from CDC's Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Interview Survey show that in 1998 approximately 45,000 people in Delaware had diabetes—30,000 who had been diagnosed and 15,000 who were unaware that they had the disease. Data from the BRFSS for 2003 indicate that in Delaware, adults age 55 and over have higher rates of diabetes (15.2% to 16.2%) than the general population (7.7%). In addition, African Americans (10.7%) and Hispanics (10.3%) have higher rates of diabetes than whites (6.9%). More than 2,500 Delaware women aged 18 to 44 were estimated to have had diabetes during pregnancy in 1998. Between 1995 and 1999, approximately 300 infants each year were born to mothers who had diabetes during pregnancy.

Many adults in Delaware do not receive the appropriate testing and treatment for diabetes. For example, one quarter of Medicare beneficiaries with diabetes aged 65 to 74 did not receive glucose tests or dilated eye exams between 1998 and 1999, and 40% did not have tests for hyperlipidemia, even though Medicare covered all of these tests for people with diabetes. One third of Delaware residents with diabetes over age 18 did not have foot exams between 1997 and 1998. These treatments and tests can decrease the risk of serious complications from diabetes, including blindness, heart attacks, and foot and leg amputations.

From 1994 to 1999, diabetes was directly responsible for more than 5,000 hospitalizations in Delaware and it was implicated as a secondary diagnosis in almost 10 times as many cases. In 1998, almost 10,000 Delawareans experienced diabetes-related disabilities and made more than 300,000 physician visits related to the disease.

Caring for people with diabetes is expensive. In the late 1990s, the total economic burden attributed to diabetes in Delaware was immense. Between 1995 and 1999, payments to Delaware hospitals for diabetes care were more than \$100 million per year. During the same time, the average payment per hospitalization for diabetes patients was between \$2,000 and \$3,000 greater than the average payment for patients without the disease. In 1997, the annual total economic cost of diabetes in Delaware was estimated to be almost \$300 million.

Text adapted from *The Burden of Diabetes in Delaware* (2002).

Disparities in Health

Although Delaware is the one of the nation's smallest states, it has very definite rural and urban populations. Sussex County, which is primarily rural, accounts for almost half of the state's area and is one of the largest counties east of the Mississippi River. The total population for the county is 141,000.

According to CDC mortality data, in 2001, Delaware had the 4th highest cancer death rate (219.3 per 100,000) in the United States. In rural Sussex County, African Americans had higher cancer death rates than whites (280.9 per 100,000 compared with 205.1 per 100,000), and from 1995 to 1999, cancer death rates for the county's whites declined, while the rates for African Americans remained stable. According to the 2001 *Delaware Vital Statistics Annual Report*, the three leading causes of death in Sussex County were all preventable diseases. They include: heart disease, which accounted for 30.7% of deaths in Sussex County; cancer, which accounted for 25.7%; and stroke, which accounted for 4.7%.

In rural Sussex County, death rates for congestive heart failure exceed those of the entire state, and heart disease is the county's most frequent cause for hospitalization. According to 2001 CDC mortality data, diabetes death rates for all racial and ethnic groups in Delaware exceeded diabetes death rates for the United States (27.1 per 100,000 compared with 25.2 per 100,000), although the diabetes death rate in Sussex County was lower than the rate in Delaware (27.1 per 100,000 compared with 29.5 per 100,000).

Other Disparities

- **Physical Activity:** Delaware's Hispanics and African Americans are less likely to meet the recommended guidelines for moderate physical activity than whites (34.5% for Hispanics and 37.0% for African Americans, compared with 45.9% for whites).
- **Obesity:** African Americans are more likely to be obese (32.8%) than whites (22.4%) or Hispanics (28.1%).
- **Cervical Cancer:** In Delaware in 2002, African American women were more likely to have had a Pap smear in the last 3 years (95.1%) than white women (91.0%); however, in 2001 African American women in Delaware had a higher cervical cancer death rate (7.0 per 100,000) than white women (4.0 per 100,000).

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For more information, additional copies of this document, or copies of publications referenced in this document, please contact the Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Mail Stop K-42, 4770 Buford Highway NE, Atlanta, GA 30341-3717 | Phone: (770) 488-5706 | Fax: (770) 488-5962
E-mail: ccdinfo@cdc.gov | Web: <http://www.cdc.gov/nccdphp>

APPENDIX 2

SUB-COMMITTEE NOTES: PREVENTION & PRIMORDIAL CARE

Describe the educational and support mechanisms in the state, particularly as they relate to high-risk populations. (May elaborate on assets identified in table above.)

Stroke screening, stroke proclamation in Newark, Wilmington and Dover, Heart conferences available for professionals, 5 K in May, “Thumbs up” support group, Easter Seals, AHA, ASA

What could we do better? What obstacles exist?

Communication statewide, Need to involve large organizations such as AARP, league of women voters, churches, schools, universities, student nurses, YMCA, insurance payers.

Educational opportunities to teach “brain attack”, lifestyle changes to decrease risk of stroke to patients and their families (to include children), public service campaign.

Need current demographic stats to provide performance improvement indicators.

Need funding.

Address disparities of targeted population.

Statewide standards of care plan systems.

Low utilization of TPA, need for education regarding quick response at both the patient and healthcare provider level.

What critical success factors need to occur before we can move forward?

Knowledge of support and funding—in particular for funds to support a “state stroke coordinator”

Action Plan			
Opportunity/Next Step	Stakeholder Organization Responsible	Name the Person/ People who will act	Follow-up required by what date?
<p>Development and funding of stroke registry and development and funding of Stroke Coordinator position, which would report under the Division of Public Health. This coordinator would:</p> <p>1) Maintain a database of state statistics such as; demographics of stroke victims, death rates, utilization of TPA and time frame, rehabilitation plan, etc.</p> <p>2) Determine screening effectiveness by development of a tracking mechanism for follow-up after detection of stroke risk factors</p>	<p>Public Health, BC/BS and other insurance providers</p>		

Education of the Public

Action Plan			
Opportunity/Next Step	Stakeholder Organization Responsible	Name the Person/ People who will act	Follow-up required by what date?
Continue smoking cessation programs, anti-smoking campaigns i.e. "The Truth Campaign" Target youth for future prevention	American Lung Association, American Legacy Foundation, Delaware Ecumenical Council for Children and Families (DECCF), Board of Education		
Education of the public regarding timely identification and diagnosis of a stroke, as well as the need for quick EMS response (send postcards with magnet attached which indicates possible stroke symptoms) "Cincinnati Pre-hospital Stroke Scale" (i.e. facial droop, pronator drift, speech) *Publish all information in English and Spanish	Dept of Public Health – Office of EMS, Public Safety Dept, and County EMS Divisions		
Education of public regarding risk factors and prevention of stroke via media such as public billboards, radio announcements. Also utilize teaching thru senior centers, schools, YMCA 's, diabetic support groups, church organizations, Consider training individuals within certain communities teach these concepts within their faith based groups or work groups etc.—(also question incorporating the CDC's Wisewoman guidelines) Development of media campaign utilizing slogan to repeat throughout all areas of the media (such as the Know Your Numbers campaign already in existence)	Division of Aging, Delaware Nursing Organization, AARP, Board of Education, American Stroke Association, The Governor's Office, Delaware Health Care Facilities Organization, long term care facilities, League of Women Voters, Nursing schools, State office of Women's Health		

Update and distribute Stroke Resource guide (possibly a condensed version for wider distribution). Look at alternative resources and literature from American Heart/Stroke Association	Delaware Stoke Initiative, American Stroke Association		
Curbing Obesity – Specifically promoting Healthy Eating, Nutrition and Exercise for Children and Adults within DE Support Legislation for restaurant labeling efforts.	Dept. of Public Health, Board of Education, Centers for Science in the Public Interest.		

Education of Physicians, Medical Staff, Insurance Companies

Action Plan			
Opportunity/Next Step	Stakeholder Organization Responsible	Name the Person/ People who will act	Follow-up required by what date?
Education of insurance companies regarding the coverage of diagnostic services, and need for reimbursement for alternative therapies such as nutrition counseling and increased physical therapy (North Carolina has increase insurance reimbursement for nutrition counseling by 75%).	Medicare/Medicaid, University of Delaware, American Rehab Association.		
Education and reinforcement of physicians and medical staff regarding the need for stroke screening (possibly provide financial incentive for stroke screenings completed and filed with the stroke registrar.	DSI, AHA, Medical Society of Delaware		

APPENDIX 3

SUB-COMMITTEE NOTES: EMERGENCY MEDICAL SERVICES

Notification/Response of EMS

This section provides insight on what an ideal state should have in place for the notification and response of EMS.

Notification/Response of EMS for Stroke: Ideal State
Processes are in place that facilitate rapid access to EMS for patients with acute stroke.
EMS dispatch uses the most current stroke treatment recommendations and dispatches EMS responders for strokes at the highest-level emergency response.
Emergency physicians are involved with stroke experts in the development of EMS stroke education materials; assessment, treatment and transport protocols for EMS providers.
All patients having signs or symptoms of stroke are transported to nearest primary stroke center.
EMS personnel can perform assessments & screening of patients for hyper-acute interventions.

The effective notification and response of EMS for stroke involves a complex interaction among the public, the applicable EMS programs and the relevant hospital emergency departments. Stroke survivors or a bystander must recognize the signs and symptoms of stroke and the importance of calling the emergency response number (911 or equivalent) immediately to help initiate effective therapy as rapidly as possible.

EMS communicators (call takers and dispatchers) play a critical role in stroke recognition and determining the timing and type of EMS response to stroke. A systems approach can help implement measures that decrease the time from receipt of a call for a probable stroke and the dispatch of EMS personnel. In the absence of ongoing stroke-specific training and feedback, communicators may fail to identify a significant percentage of potential strokes even when callers spontaneously use the word “stroke” in communicating with the dispatcher.

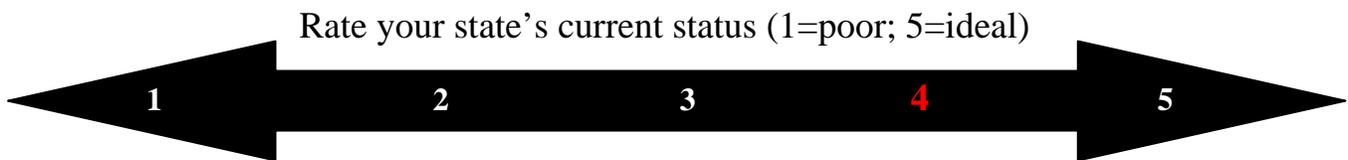
Establishing programs that provide ongoing education for field EMS personnel to facilitate the accurate and rapid recognition of patients with acute strokes is essential to promote appropriate decisions involving the treatment, transport and destination of suspected stroke survivors. Although EMS responders frequently fail to identify strokes when support mechanisms are not in place, stroke recognition tools have been developed that assist EMS personnel in identifying patients with acute cerebral ischemia and intracranial hemorrhage with high sensitivity and specificity.

Recognition of stroke by EMS personnel is needed to guide both the transportation of patients to the most appropriate facilities and the initiation of stroke-specific basic or advanced life support prior to arrival at the hospital. Effective communication between EMS responders and receiving emergency departments is important in optimizing the efficiency of the hospital's response to acute stroke. Time is saved when notification from EMS enables the emergency department to begin assembling the necessary personnel to treat an acute

stroke patient. EMS responders and communicators also can play an important role in collecting information about the time of the onset of stroke symptoms. Such data can be essential to clinical decision making in the acute treatment of stroke.

There are potential benefits from coordinating air transport options with EMS to enhance stroke care. The use of helicopter-based transportation offers the potential to expand access to stroke therapies and services that are not widely available to patients in some rural and other neurologically underserved areas. When initiated quickly as part of a collaborative inter-facility system, helicopter-based transportation can reduce the time to emergency department arrival at hospitals that are equipped to treat acute stroke survivors.

Notification/Response of EMS for Stroke: Continued



The notification/response of EMS for stroke is rated at a 4. Delaware's system meets the threshold criteria including:

- 1) Processes are in place for rapid access to EMS;
- 2) Protocols match, and often exceed, current recommendations;
- 3) Although there are no certified stroke centers in Delaware, transport to the nearest CT-capable hospital is the norm, and;
- 4) EMS personnel receive regular periodic screening to assess/screen and identify stroke.

Assets/Resources Available for this Component	
Organization	Key Components to achieve successful system of care
EMS agencies (ALS, BLS, PSAP etc..)	
Other DPH	
Hospital Emergency Departments	
State EMS Medical Directors	

Describe the general EMS environment in our state.

The EMS system in Delaware is commonly known as a “two-tiered” system, meaning that two different levels of providers respond to emergency calls. The nature of the emergency is determined by the Emergency Medical Dispatch System. This determination is then used to dispatch the appropriate level of response.

The first of these levels is known as Basic Life Support, or BLS. BLS responders provide ambulance transport, and are typically dispatched on all emergency calls. The 51 BLS agencies are affiliated with the fire service or else exist as an independent local ambulance provider. The City of Wilmington and Dover contract with commercial ambulance services for their emergency BLS response. The Delaware State Fire Prevention Commission is an independent state agency that oversees and regulates BLS operations, ambulances and apparatus, and manages all ambulance licensing and certification. BLS responders include the “Emergency Medical Technician-Basic (EMT-B)”, and the “First Responder”. Each type of BLS responder is trained to a different level, with the EMT-B being the highest level of BLS training.

The second tier in the system is known as Advanced Life Support, or ALS. The ALS responder is known as an “Emergency Medical Technician-Paramedic (EMT-P)”, or “Paramedic” (the terms are synonymous). Paramedics are trained to a higher level than BLS providers and are dispatched to the most serious medical emergencies. Most paramedics certified in Delaware are employed by one of the certified ALS agencies, one located in each County, or the Delaware State Police Aviation Section. Two private ALS providers, Christiana Care LifeNet and Washington Hospital Medstar, also employ paramedics and provide ALS helicopter transport in Delaware. The State EMS Office within Delaware Health and Social Services’ Division of Public Health is the lead agency for Advanced Life Support activities. The Office monitors the availability of EMS services throughout the state, ensuring appropriate coverage, and coordinating EMS training and certification. The Office also provides all medical direction for the Emergency Medical Dispatch System, BLS, and ALS. Each ALS agency has a state-assigned medical director. The State Fire Prevention Commission also has a state-assigned medical director for BLS issues. Christiana Care’s LifeNet and Washington Hospital’s Medstar, employ state-approved medical directors. Delaware has 8 general acute care hospitals, 961 First Responders, 1,138 EMT-B’s, 246 EMT-P’s, 17 ALS units, 51 BLS agencies, and 2 air medical agencies.

The Office of Emergency Medical Services is a section within the Division of Public Health, Department of Health and Social Services. It plays a vital role in the integration of emergency medical services into the state’s public health system. The goal of the Office of Emergency Medical Services (OEMS) is to provide resources, coordination and oversight of the Emergency Medical Services Systems (EMS), resulting in a reduction of death and disability in the State of Delaware. The OEMS coordinates with other state agencies, hospitals and laboratories to ensure that the citizens of our state are provided quality pre-hospital care. The OEMS is a catalyst for EMS system improvement and sustainability.

OEMS oversees programs including:

Advanced Life Support Services (ALS) - The ALS (Paramedic) Program is considered by many to be a state of the art program that ensures highly trained paramedics are providing

quality emergency care to the citizens and visitors to our state. The OEMS is responsible for coordination of training, certification, financing and oversight of the state's paramedic system.

Statewide Trauma System & Injury Prevention - The Division of Public Health, Office of Emergency Medical Services was mandated in 1996 (Title 16, Chapter 97) to develop, implement, and maintain a Statewide Trauma System. This program is responsible for coordination of hospitals and provider agencies to ensure optimal care for trauma patients, and serves as a leader in statewide injury prevention efforts.

Emergency Medical Services Data Information Network (EDIN) - This program is responsible for maintaining a system of electronic data submission for EMS patient care reports and is the basis for EMS quality assurance and assessment of training needs. The EDIN system has been utilized nationally as a model for patient care reporting.

EMS Medical Direction - This program is responsible for providing medical oversight of the statewide EMS system (ALS and BLS), review and modification of the Statewide Standard Treatment Protocols, oversight of Medical Command Facilities, conducting research and oversight of the statewide EMS Quality Assurance program. The primary role of the medical director is to ensure quality patient care.

First State, First Shock Early Defibrillation Program- Delaware recognizes the need for a statewide plan for reducing death and disability associated with cardiac arrest. The EMS Improvement Act of 1999 charged OEMS with coordinating a statewide effort to promote and implement widespread use of AEDs, including increasing the number of publicly available AEDs. This program is responsible for providing data collection, training and prevention activities in support of initiatives to reduce cardiac arrest deaths in Delaware.

In addition to these programs, the Office of Emergency Medical Services promulgates and implements regulations overseeing:

- *Air Medical Ambulance Services*
- *Advanced Life Support Inter-facility Transfers*
- *Early Defibrillation Providers*
- *Prehospital Advanced Care Directives.*

Delaware EMS Oversight Committee

DEMSOC was created in 1999 to promote the continuous development and improvement of our Emergency Medical Services (EMS) System. The membership of DEMSOC includes professionals from several EMS provider agencies, representatives from agencies that frequently work with and support EMS, and private citizens knowledgeable in the delivery of EMS care. The Council meets several times throughout the year to address current issues and provide support for developing workable solutions to those issues.

Describe the processes that are in place that provide rapid access to EMS for patients with acute stroke.

Emergency Medical Dispatch

All public safety answering points (PSAP) that dispatch ambulance personnel are required to use the Priority Medical Dispatch System (PMDS) version 11.3. (Priority Dispatch Corporation; Salt Lake City Utah, USA; release date: July, 2006) This latest version contains updated stroke protocol key questions for stroke onset timeframe identification, and had questions regarding vision problems and sudden onset severe headache codes added. All dispatchers employed at those PSAPs must be certified Emergency Medical Dispatchers (EMDs). EMD training is provided on an as-needed basis by in-state EMD trainers.

Identify the EMS dispatch protocols.

EMS Dispatch and Acute Stroke. Dispatch is often able to identify stroke survivors while still in the field which then causes EMS to be alerted to the possibility of a stroke patient. Stroke is a time-sensitive medical emergency and should be responded to with a sense of urgency comparable to that used in response to chest pain suspected to be due to myocardial infarction. Therefore in the absence of additional priority symptoms, for both chest pain and stroke the EMD protocol calls for dispatching an ALS-level response without the use of lights and siren.

- Priority Medical Dispatch System (PMDS)
- Contains updated stroke protocol;
 - Key questions for stroke onset timeframe identification
 - Questions regarding vision problems
 - Questions regarding sudden onset severe headache

Where are suspected stroke survivors transported?

Paramedics have standing orders to transport a patient suspected of having a stroke is to the nearest appropriate *CT-capable* medical facility without delay.

What could we do better? What obstacles exist?

Education is the key. Delaware has a progressive EMS system however the citizens of DE have to make the call to 911 to benefit from our progress.

Paramedics in the state go through a comprehensive continuing education program developed by Delaware Tech and Community College under a contractual arrangement with the OEMS. All paramedics in the state are paid personnel, Delaware has no volunteer paramedics. EMS training curricula has been modified to place more emphasis in the areas of stroke. Paramedics are required to use the Cincinnati Pre-hospital Stroke Scale in their assessment of patients with presumed stroke. EMS providers should attempt to identify the time of onset of symptoms. In addition, the Delaware EMS Medical Director recommends consideration of transporting a witness (family member, co-worker etc) with the patient to assist with the gathering of time-sensitive information.

The basic level providers in many cases are volunteers, development of alternative methods of training such as video or on-line education would prove to be a great asset to this group of providers. Currently, Dispatchers and EMTs have limited instruction on stroke diagnosis and

management which may contribute to a small number of acute stroke survivors arriving in the ED within the therapeutic window.

Obstacles include:

- 1) Lack of awareness among the general public of signs/symptoms of stroke and the need to call 911 immediately if these are present.
- 2) Lack of resources to enhance services such as air transport; or to create integrated data systems to more effectively track outcomes for stroke survivors as they move from EMS to the emergency room and/or inpatient status.

What critical success factors need to occur before we can move forward?

Action Plan			
Opportunity/Next Step	Stakeholder Organization Responsible	Name the Person/ People who will act	Follow-up required by what date?
Develop a stroke awareness campaign focused on signs/symptoms and 911 usage	DPH OEMS & Chronic Disease Bureau	Steven Blessing, Diane Hainsworth and Alisa Olshefsky	Date to be established once funds are identified
Create a cardiac and stroke event registry	TBD once funds are identified	TBD once funds are identified	TBD once funds are identified
Implement a data exchange system between OEMS and hospital emergency rooms to track outcomes for stroke survivors. Close the data gap.	DPH OEMS &	TBD once funds are identified	TBD once funds are identified
Determine the feasibility of using nationally recognized stroke scales	DPH OEMS	Steven Blessing, Diane Hainsworth	TBD

APPENDIX 4

SUB-COMMITTEE NOTES: ACUTE & SUB-ACUTE CARE ACUTE TREATMENT FOR STROKE

Assets/Resources

Delaware Office of American Stroke Association
Delaware Stroke Initiative
Delaware Neurologists
Delaware Neurosurgeons
Delaware Hospitals
Department of Emergency Medical Services

Key Components

Requires an organization that is permanent and meets regularly to discuss stroke treatment in Delaware. This would ideally be directed by state organization and have representatives from all Delaware hospitals and physicians who care for stroke patients. This would allow statewide coordination of care, sharing of best practices and appropriate triage of patients.

Improvements/Obstacles

Better organization of the response to stroke is needed with well trained stroke teams, stroke units. Clearly established protocols and guidelines for evaluation and treatment of stroke that are evidence based. A responsible person or committee in each hospital that treats stroke patients is needed to insure proper training, quality assessment and improvement and to periodically evaluate and revise treatment protocols. Implement, to the best extent possible, uniformity of treatment across the state. One means to achieve this goal would be for appropriate hospitals to become certified as Primary Stroke Centers. Triage of patients by EMS to the closest appropriate hospital to allow the most rapid evaluation possible will be important. There is currently little communication between hospitals. Funding and manpower will be obstacles to certification of hospitals and designation of supervisory personnel. Better coordination with EMS will be needed. Smaller, more rural and remote hospitals will need to have their stroke care resources examined and changes made as deemed appropriate. All hospitals need to be surveyed regarding stroke care practices and potential areas of improvement identified. This will be a critical factor allowing continued quality improvement. Participation from each hospital and neurologists and other physicians treating stroke at all hospitals will be critical.

Action Plan Ideas

Survey all state neurologists requesting information on stroke treatment at their hospitals. Also solicit their participation with Stroke Plan committee. Encouraging appropriate hospitals to become Primary Stroke Centers (PSC) and determining how patients can best be triaged to these centers. Discussion on what patient criteria would determine rapid transfer to a PSC and how this would be achieved. Information from the questionnaire and follow up phone calls/emails would be used to fashion the plan for future improvements. A preliminary survey was administered in October 2006 to all of the hospitals in Delaware to assess basic stroke treatment capabilities for the purpose of this report. The results have been provided by the Delaware Healthcare Association and may be found on Page 56.

Delaware Hospital Name ²¹	City	Does hospital have a Stroke Unit?	Does hospital have a Stroke Team?	Is TPA available for treatment?	Is there a written protocol for treatment of stroke with TPA?	Is computed tomography (CT Scan) of the head available 24 hours a day?	Is a neurosurgeon available at your hospital?	Neurologist on-call 24-hours a day to treat patients?	Does hospital have written guidelines for evaluation and treatment of stroke?	Estimated number of stroke patients seen in 2005
Al DuPont Children's Hospital	Wilmington	NO	NO	NO	NO	YES	YES	YES	NO	Very rare - difficult to estimate
Bayhealth - Kent General Hospital	Dover	NO	NO	YES	NO	YES	NO	YES	NO	152
Bayhealth - Milford Hospital	Milford	NO	NO	YES	NO	In-house CT tech until 1am, then on-call tech with a 30 minute availability	NO	YES	NO	61- over 6 month period
Beebe Medical Center	Lewes	NO	Currently developing- Have a champion & members established and are writing protocols	YES	YES	YES	NO	YES	In process of establishing new guidelines	184
CCHS ²² – Christiana Hospital	Stanton	YES	YES	YES	YES	YES	YES	YES	YES	850
CCHS - Wilmington Hospital	Wilmington	NO	YES	YES	YES	YES	YES	YES	YES	200
Veterans Affairs Hospital	Wilmington	NO	NO	NO	NO	NO	NO	YES	NO	10-15 new stroke patients per year
Nanticoke Memorial Hospital	Seaford	NO	NO	YES	YES	YES – Also developed an expedited protocol for its use in stroke & potential TPA	NO	NO	YES - for TPA candidates	270
St. Francis Hospital	Wilmington	YES	YES	YES	YES	YES	YES	YES	YES	100

²¹ Survey results provided by Delaware Healthcare Association (November 2006)

²² CCHS = Christiana Care Health System

Hospital Response Phases

- Notification
 - Pre-hospital care vs. “walk-ins”
- Identification
 - Patient, Triage, Physician
- Determination
 - Rapid Testing
- Decision Making

Barriers exist at all levels

- Similar to the chain of survival for Acute MI
- Some are patient dependent
- Some are facility dependent
- Some are practitioner dependent
- Some are system dependent

Barriers at Notification stage

- Patients may not recognize their illness
 - Self present many hours after onset of symptoms
- Patients may awaken with symptoms
 - Critical time period may have passed during sleep
 - Time of onset must be assumed to have just followed the patient going to sleep.
- Dispatcher or EMS may not recognize stroke symptoms.
 - Less of an issue with extensive training.

Barriers at Identification Stage

- Patient
 - Denial, lack of awareness, lack of access
- Triage
 - Phone: description may not give all symptoms
 - Failure to recognize subtle symptoms
 - ED volume issues: delay to be seen at busy times
- Physician
 - Underestimating severity
 - Younger patients may have risk undervalued

Barriers at Determination Stage

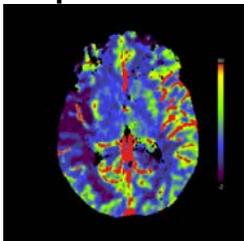
- Rapid CT with detailed reading
 - Hospital programs which expedite CT scan for suspected stroke patients can improve performance
 - Neuroradiologist reading preferred
 - Must rule out even the smallest area of bleeding
- New CT scans show perfusion of areas of the brain
 - Higher reliability and physician confidence

Initial Diagnostic Evaluation

- Non-contrast CT is key
 - Readily identifies blood
 - Size and location of hemorrhage
 - May expose contributing structural abnormalities
 - ◆ Tumor
 - ◆ AVM
 - Reveals structural complications
 - ◆ Herniation
 - ◆ Intraventricular hemorrhage
 - ◆ Hydrocephalus



CT perfusion scan



Barriers at Decision-making stage

- Therapy choices have high risk
 - Thrombolytics can lead to intracranial hemorrhage
 - ◆ In fact, CVA is a relative risk to thrombolytics
 - Any uncertainty can lead to increased risk of hemorrhage:
 - ◆ potential for incorrect time of onset
 - ◆ unappreciated bleed on CT
 - ◆ larger area of brain affected
- Risk may be as high as 6% to have symptomatic hemorrhage

t-PA Meta-Analysis

- 2639 patients
- Death rate 13.4%
- Recovery rate 37.1%
- Protocol deviations 19.8%
- Mortality correlated with protocol deviation

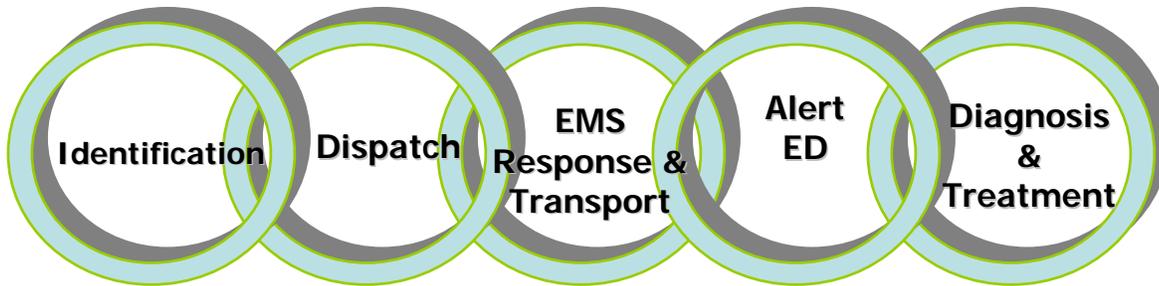
Graham - *Stroke* - 2003; November (pre-released)

Medical/Legal Pitfalls

- Informed Consent
 - Patients or their proxies should be allowed to decide whether to accept or reject a treatment option
 - t-PA can harm, be sure that patients clearly understand its risks and benefits, and give their informed consent before it is administered
 - Many EDs in the US have instituted policies requiring neurologists to administer t-PA in order to shift any medicolegal risk should an adverse outcome occur

Where do we go?

- Educate patients and providers
 - Just as with MI, patients must recognize and activate 9-1-1
 - Stroke Chain of Survival



Pepe PE. Ensuring the chain of recovery for stroke in your community. Acad Emerg Med 1998;5(4):352-8

Where do we go?

- Determination enhanced with hospital programs to expedite diagnosis and care:
 - Designation as “stroke center”?
 - Best Practices modeling for all hospitals?
 - Stroke “system” like trauma system?
 - What is the role of these centers: acute treatment or recovery?
- Decision making: are thrombolytics the best option?

Future Directions

- PSA campaign or pamphlets at health care or other public centers to improve patient and family recognition.
- Best practice models for hospital programs to expedite diagnosis and care
- Continue to research acute therapy options: are reperfusion options with directed thrombolytics or intracerebral angioplasty/stents the better answer?
- Continue to research post treatment interventions to limit damage: may be the true value of “stroke center”

APPENDIX 5

SUB-COMMITTEE NOTES: REHABILITATION

Describe the current rehabilitation environment in our state.

- Good quality inpatient rehabilitation appears to be available in Delaware, primarily at Wilmington and Milford Hospitals. However, there are gaps in the system. SNF, home health and outpatient services are not integrated and have varying expertise in treating patients with a stroke. Patients in more rural areas may have limited access. Minimal number of beds available at St. Francis, but this appears to be due to need, and Nanticoke (sub-acute). Question how many patients go to Bryn-Mawr Rehab or McGee in Philadelphia.
- Not everyone is referred to the appropriate level of care – particularly those with the milder and the most severe CVAs, and those who have deficits that are more in the cognitive or speech realm.
- Patients who are referred initially to Skilled Nursing Facilities (SNF) because they are too sick for Rehab often fall through the cracks. They are often not referred back to intensive inpatient Rehab when they later become well enough to participate.
- Rehab is often cut short by reimbursement issues.
 - Managed care is worse than Medicare, often limiting treatment to 24 visits in a 60 calendar day period per condition per life, which is inadequate for rehabilitation of most individuals with a stroke. If a patient gets sick midway through the 60 day period of treatment and doesn't recover until after that period, he/she may not even get the 24 days. This is a significant problem. For example, Blue Cross Blue Shield of Delaware insures > 30% of Delawareans.
 - Given the limited time allowed for treatment per condition, there is often an emphasis on teaching patient's compensations for their impairments rather than helping them gain as much functional use of the affected extremity as possible. This is particularly true for arm function. Some managed care agencies require patients to be discharged as soon as they are able to walk 50 feet with minimum assistance.
 - Managed care companies typically dictate where the patient must go for outpatient rehab, and the required facilities are often not equipped to treat complicated neurological cases, focusing instead on orthopedic and sports medicine cases.
 - Although co-treatment by OT and PT may be beneficial for a patient, most insurance companies have billing practices that prevent appropriate billing for the therapists' involvement.
 - Cost to patients is increasing. Some patients have co-pays up to \$30 per visit because of limited contribution by managed care companies.
 - Medicare has a therapy cap, but there is currently an exception for individuals with a CVA. However, many therapists and physicians are unaware of this extension which requires documentation, and the patients may suffer. This exception is due to expire on December 31, 2006 without Congressional action.

- It was suggested by one member of the panel that there is a lack of adequate push to get patients into intensive inpatient rehab after a stroke despite evidence that patients who get such care do better in the long-run, other things being equal, compared to those who do not. On the other hand, because of the recent 75/25 Medicare case mix requirement for inpatient rehabilitation, many less complex diagnoses are no longer appropriate for the rehab unit and this creates more room for patients with stroke.
- Short staffing of some facilities leads to gaps in care, particularly in the hospital and home health settings. Despite the fact that individuals with a stroke commonly have problems with depression, patients who are not sent to inpatient rehab often do not have access to a rehab psychologist. Evaluation by a qualified psychologist early on would also help identify cognitive problems that complicate rehabilitation and functional recovery.
- Patients receiving treatment in home health care settings and private practices in Delaware often do not have access to all relevant disciplines (OT, PT and SPT). It was reported that none of the private practices in southern Delaware have all three disciplines available to patients. Even when they are available, there is frequently not a team approach to treatment. Therefore, except perhaps in the primary inpatient rehab settings, lack of coordination among the disciplines appears to be a problem.
- There is a perception that a lack of communication exists between facilities regarding the sharing of patient records for therapy. Therapists in one facility (e.g. home care or outpatient rehabilitation) often get minimal information about the patient's treatment plan from another facility from which they were discharged.
- There was a perception that the rehabilitation care provided by therapists is uneven and, in some cases, antiquated.
 - To what extent do therapists engage in evidence-based practice? One committee member suggested that most therapists are not adequately trained to engage in such practice.
 - Limited continuing education provided by agencies providing therapy to help therapists keep up to date with practice issues – but how much is the therapist's responsibility? May be particularly a problem when continuing education requires substantial travel.
 - When therapists attempt to implement evidenced practice ideas, they are often thwarted by the lack of funds to buy necessary equipment. A good example is body-weight supported treadmill training.
 - Newer therapeutic approaches that are based on scientific evidence frequently are not covered by insurance for reimbursement.
 - There is a lack of time and support provided by health care providers to allow for clinical research into issues of most importance to stroke rehabilitation. At the same time, there is inadequate collaboration between academic and clinical sites to accomplish clinical research.
 - Experimental evidence is increasingly finding that repetition is the key to improvement of function. Most rehab facilities do not provide adequate repetition for patients to achieve maximum recovery of function. This fact may not be adequately emphasized to the patient and his/her family and there may be inadequate follow up in the home to ensure that there is adequate carryover there.

- The lack of a stroke registry makes it difficult for facilities who are engaged in research to improve the quality of rehabilitation to identify appropriate patients for study. Moreover, a registry with some means of tracking patients may help prevent patients from falling through the cracks. In addition, a registry of health professions (i.e. PT, OT, SPT, rehab psychology) qualified to treat stroke could help ensure that patients receive treatment from individuals most appropriate to treat their problems.
- There is a need to define more scientifically categories of stroke and how different categories best respond to different treatments. Related to this, there is a need for a single, comprehensive functional classification system that is used by all facilities. At present, different systems (OASIS, FIM, MDS) are used by different facilities (e.g. SNFs, inpatient rehab, home health care). One suggestion was the international ICF scale (International Classification of Function).

Rehabilitation of Stroke Survivors: Continued	
Assets/Resources Available for this Component	
Organization	Key Components to achieve successful system of care

What critical success factors need to occur before we can move forward?

Action Plan			
Opportunity/Next Step	Stakeholder Organization Responsible	Name the Person/ People who will act	Follow-up required by what date?

The following recommendations resulted from Rehabilitation sub-committee meetings held on June 26 and August 15, 2006.

1. This recommendation** was based on the premise that the State of Delaware is committed to developing a stroke registry. The recommendation attempts to rectify the current problem of accurately tracking a patient's functional progress as they move through the system, from one treatment setting to another (i.e. skilled nursing home, inpatient rehab center, and outpatient care). The subcommittee felt that it was critical to find ways to document which pathway of care provides the greatest likelihood of improved function. This is currently difficult, in part, because assessment instruments used across settings are different and non-commensurate (i.e. FIM, MDS, OASIS). The committee felt that it would be ideal for all treatment facilities to eventually use the Activity Measure for Post-acute Care (AMPAC) at least as a supplement to current assessment tools. However, it is recognized that it will take time and additional supportive data to convince facilities to use this tool and it will be difficult or impossible to dictate this. Thus, we recommended that the State of Delaware dedicate personnel involved as case managers within the mechanism of the proposed stroke registry to ensure that all identified patients are provided with a copy of the AMPAC short form to be filled out initially (by stroke survivors and/or their families), to be updated whenever the patient changes treatment options or is discharged from treatment. The data from this assessment would provide a data base that would provide a means to identify the consistency or breakdowns along different treatment pathways. This process could be facilitated by making the assessment available on line to patients and their families. In time, data collected through this process may help to establish the most appropriate pathways of care for different levels of initial functional ability. This data could be used, for example, by the insurance commissioner to pressure third party payers regarding the appropriate settings/pathways for care. (The last comment is based on the point that 3rd party payers typically dictate which facility a patient can go to for out patient therapy, even though that facility may not be optimally qualified to treat such patients).

** According to Dan Ciolek, Rehab Subcommittee member, here are current considerations to use the ICF (International Classification of Function) standards to make decisions related to the Medicare program. The AMPAC is a tool recently developed by Alan Jette and others at Boston University. It has a dual purpose, which is to help measure rehab functional change over time and to help determine which facility would be optimal for a patient's care. Quality of care was the prime driver for this tool, although it may also be used by Medicare as a method to determine reimbursement. Dan suggested that AMPAC is based on solid research and comes in a short form that is relatively easy to administer. This assessment can potentially be filled out by the patient him/herself or a family member, or with the assistance of a social worker. Reliability data on the AMPAC from Jette's group indicates that it is just as accurate as the inpatient FIM, the skilled nursing facility MDS form, and home care OASIS form. Advantages are that the assessment is applicable to multiple settings from acute rehab, through nursing home, home health and outpatient rehab facilities.

2. The Centers for Medicare & Medicaid Services recently announced a call for a demonstration project that will develop and assess the effectiveness of a post-acute

care assessment instrument. Dan Ciolek indicated that this call appeared to be targeted specifically for Jette's group at Boston University to support their development of the AMPAC. After discussion, the subcommittee felt that the state of Delaware would be wise to get on board by contacting our Congressional representative, Mike Castle, to make him aware of the state's desire to participate in this demonstration project, as well as to contact Jette to lobby him about the uniqueness of our state as a potentially ideal state to carry out a demonstration project. Pursuing this avenue might provide a means for obtaining some funding to help get recommendation #1 off the ground as well as being in a good position to compete for future federal dollars.

3. The subcommittee identified the need to increase the evidenced-based practice by therapists in the state of Delaware. An impediment is provided by the facts that 1) many rehab facilities have reduced both compensation time and financial support for continuing education, 2) there are few appropriate continuing education courses related to stroke assessment and treatment offered in Delaware and surrounding areas, requiring significant travel and substantial financial investment by therapists, 3) therapists often have access only to one professional journal, i.e. related to the professional association to which they belong. These facts make it difficult for therapists to keep up with current advances in assessment and treatment. The subcommittee recommended that the Department of Health make a concerted effort to provide for more continuing education opportunities in the state for such purposes that are related specifically to the rehabilitation of patients at different stages of recovery from stroke and/or brain injury. The Delaware Stroke Initiative already contributes to this endeavor by their annual fall stroke conference. However, the focus of this conference is not on rehabilitation. Brenda Grassett, Rehab subcommittee co-chair member recently applied for and received a small grant from Delaware Technical College to help mount a rehabilitation conference. She and John Scholz will work on developing a program for 2007. However, continuing efforts of this nature would be greatly enhanced by support from the State. Another recommendation was for the Department of Health, perhaps in conjunction with the University of Delaware, to help make rehabilitation journals available on line to therapist licensed in the State of Delaware so that have available appropriate literature to read. Because the University already provides access to many on line journals for employees and students, the funds required to extend this service to health care professionals who are licensed in the State may be relatively minimal.
4. It was suggested that the State of Delaware work with Blue Cross/Blue Shield to allocate some of their end-of-year reserve for stroke care as a carve-out diagnosis. It was mentioned that BCBS used end-of-year funds in the past to help defray the cost of malpractice insurance for physicians. Given the limitations on long-term treatment access for stroke and the fact that BCBS insures such a large number of Delawareans, the State may be able to convince them of this use of the reserve. In addition, it may be possible to get BCBS on board to help collect data on the AMPAC on patients insured by them.
5. It was recommended at the June 26 meeting that the State bring together members of the different health professions to make recommendations about the kinds of data that

should be collected to help case managers plan and better evaluate stroke rehabilitation services offered in the state. The committee suggested that the state fund 'case managers' to follow patients through the continuum of care. This process and the stroke registry could provide the state with good data for future change.

6. Another recommendation was for the State Department of Health to put together a task force to explore how to increase representation of occupational and speech therapy in more remote regions of the state where patients often have to wait up to a month or more before obtaining access to these disciplines because of the shortage of these health professionals in the state. It is important to address this issue promptly.
7. A final recommendation, related to recommendation #3, was for the State to engage in dialogue with the Provost and appropriate departments at the University of Delaware about the possibility of collaborating on the development of a rehabilitation research and treatment center at the University, dedicated to stroke and brain injury. Although stroke-related rehabilitation research is taking place at a number of sites throughout the country, it often takes a substantial amount of time for the results of such research to filter down to therapists and to effect patient care. Of course, this limitation would not be eliminated by establishing a rehabilitation/research center in Delaware. However, a state-of-the-art, combined research and treatment center in the state of Delaware would allow for appropriate patients to receive rehabilitation care while at the same time participating in the development of novel treatment approaches, as well as enhancing the possibility of increased funding for efforts to advance stroke rehabilitation in the state. This possibility already exists on a limited basis as several faculty members at the University of Delaware are engaged currently in a variety of federally funded studies on stroke rehabilitation. The limited existing rehabilitation centers located in Delaware are unlikely to make such research a priority given their financial and personnel constraints. The University of Delaware is in a unique position to take on this endeavor given that a physical therapy department already exists on campus and it is already engaged in rehabilitation research. There is also discussion underway for establishing a speech therapy program at the university. Support for such a center could be part of a broader State plan to obtain funding through the proposed Stop Stroke Act when those monies become available. A dedicated rehabilitation research and treatment facility would provide a mechanism to foster ongoing and future research and provide the possibility for faster dissemination of new treatment methods to therapists in Delaware and, subsequently, to stroke survivors.

APPENDIX 6

SUB-COMMITTEE NOTES: CONTINUOUS QUALITY IMPROVEMENT

Stroke Continuous Quality Improvement Initiatives: Ideal State

A stroke system should strive to optimize the overall effectiveness of the system and each of its individual components. This goal should be accomplished by identifying performance measures for each component and for the system function as a whole (both process and outcomes measures) and by employing CQI strategies in collaboration with key stakeholders.

A critical function of a systems approach to stroke care is the use of continuous quality improvement (CQ) strategies to ascertain whether and to what extent various efforts are succeeding in improving patient care. CQI relies on HIPAA compliant data accessibility and transfer among all appropriate facilities and providers.

Both process and outcome measures should be developed to measure implementation of services, linkages among key stroke system components, obstacles to care, potential gaps, and most importantly- patient outcomes.

In general, measurable outcome variables for stroke survivors include:

- Mortality
- Functional status
- Discharge destination (i.e. community or institution)
- Discharge to home
- Quality of life

In general, process of care variables include:

- Demographics
- Co-morbidities
- Diagnosis codes
- Length of hospital stay

The table below includes sample performance measures for each of the key stroke system components. This list is not intended to be inclusive and will be supplemented by each respective committee.

Performance Measures		
Stroke Plan Component	Measure Type	Measure Description
Primordial and primary prevention	Process	<ul style="list-style-type: none"> • Reach of distribution of new stroke prevention strategies • Number of providers aware of emerging stroke prevention strategies • Number of providers implementing in a systematic way the emerging strategies (pre/post intervention)
Primordial and primary prevention	Process	<ul style="list-style-type: none"> • Reach of community education activities, especially among at-risk populations • Percent change in knowledge and attitudes about the causes, signs and symptoms of stroke among sample population
Primordial and primary prevention	Outcome	<ul style="list-style-type: none"> • Number of deaths averted due to early sign/symptom awareness
Notification of Emergency Medical Services	Process	<ul style="list-style-type: none"> • Development of data exchange system between EMS and hospitals (yes/no) • Data quality as measured by inter or intra-rater reliability assessment • Time to CT capable emergency room
Notification of Emergency Medical Services	Outcome	<ul style="list-style-type: none"> • Increase # of stroke victims who present in ER Dept. w/in 3 hours of symptom onset
Acute and sub-acute stroke treatment	Process	<ul style="list-style-type: none"> • Time between identification of stroke and delivery of acute treatment of both ischemic and hemorrhagic stroke
Acute and sub-acute stroke treatment	Outcome	<ul style="list-style-type: none"> • % increase in positive patient outcomes due to appropriate tPA use • % decrease in complications prevented due to effective acute treatment
Rehabilitation	Process	<ul style="list-style-type: none"> • Number of stroke survivors who receive and initial evaluation for rehab therapy during initial hospitalization • Care plans for stroke survivors discharged from hospitals including identified support systems, primary and follow-up care
Rehabilitation	Outcome	<ul style="list-style-type: none"> • % decrease in mortality • % of stroke survivors who recover activities of daily living

APPENDIX 7

State Program: Ohio Capacity Building

The Ohio Department of Health began receiving funds from CDC in 2000 to support a state heart disease and stroke prevention program.

Burden of Heart Disease and Stroke

- Heart disease is the leading cause of death in Ohio, accounting for 31,388 deaths or approximately 29% of the state's deaths in 2002. (*National Vital Statistics Report 2004;53(5)*).
- Stroke is the third leading cause of death, accounting for 7,252 deaths or approximately 7% of the state's deaths in 2002. (*National Vital Statistics Report 2004;53(5)*).
- According to Behavioral Risk Factor Surveillance System (BRFSS) survey results in 2003, adults in Ohio reported having the following risk factors for heart disease and stroke:
 - 26.2% had high blood pressure
 - 33.8% of those screened reported having high blood cholesterol
 - 8.8% had diabetes
 - 25.2% were current smokers
 - 60.9% were overweight or obese (Body Mass Index greater than or equal to 25.0)
 - 26.4% reported no exercise in the prior 30 days
 - Approximately 84% had one or more of these six risk factors.

Key Responsibilities

- Facilitate collaboration among public and private sector partners, such as managed care organizations, health insurers, federally funded health centers, businesses, unions, school systems, priority population organizations, and emergency response agencies.
- Define the cardiovascular disease (CVD) burden and assess existing population-based strategies for primary and secondary prevention of heart disease and stroke within the state.
- Develop and update a comprehensive state plan for heart disease and stroke prevention with emphasis on developing heart-healthy policies, changing physical and social environments, and eliminating disparities (e.g., based on geography, gender, race or ethnicity, or income).
- Identify culturally appropriate approaches to promote cardiovascular health with racial, ethnic, and other priority populations.
- Use population-based public health approaches to increase public awareness of the urgency of addressing CVD, the signs and symptoms of heart disease and stroke, and the need to call 9–1–1.

State Highlights

- Ohio is part of the Great Lakes Stroke Regional Network funded by CDC in 2004. The Network is led by the Illinois Department of Public Health and also includes Indiana, Michigan, Minnesota, and Wisconsin.
- *Cardiovascular Disease in Ohio 2001: A Profile of Cardiovascular Disease Mortality and Related Behavioral Risk Factors* has been published and distributed to state partners. This document describes the burden of cardiovascular disease in the state and notes disparities based upon race and geographic location within the state. Using BRFSS data, the publication presents trends in modifiable risk factors such as high blood pressure, poor dietary habits, and physical inactivity. This publication is available on the Ohio Department of Health Web site (see link below).
- The program has identified its priority populations based upon differences in cardiovascular mortality rates identified through analysis of death certificate data: Black males have a rate 10 percent higher than white males and Black females have a rate 20 percent higher than white females. High mortality rates were also found in southeastern Ohio counties. These counties are in the region designated federally as Appalachia. A subcommittee of the Ohio Cardiovascular Health (CVH) Alliance has been established to identify and make recommendations for culturally-appropriate intervention strategies to address heart disease and stroke among these priority populations. The recommendations will be included in the Ohio CVH State Plan.
- *The Ohio Plan to Prevent Heart Disease and Stroke 2002–2007* has recently been published. The plan is a result of a coordinated, cooperative effort of all members of the state coalition. An evaluation plan designed to assess adherence to recommended primary and secondary prevention standards of care was written into the plan. The plan is also available on the Ohio Department of Health Web site.

For more information on heart disease and stroke prevention in the state, visit the Ohio Cardiovascular Disease Risk Reduction Program Web site at <http://www.odh.ohio.gov/odhPrograms/hprp/cardio/cardio1.aspx>.*

APPENDIX 8

PROPOSED PENNSYLVANIA STROKE OFFICE LEGISLATION

Draft legislation establishing an office devoted exclusively to stroke, patterned after the Ohio statute. The council would be under the administrative control of PADOH as the lead agency for stroke programs. The membership of the advisory council is set forth in section 4(b) of the proposed act and comprises a broadly inclusive list of public agencies and representatives of the associations most concerned with stroke care.

Under the proposed legislation, the council has the following responsibilities:

1. Developing and implementing a comprehensive public education program on stroke prevention, targeted to high-risk populations and to geographic areas where there is a high risk of stroke, including information developed or compiled by the council on healthy lifestyle practices, signs and symptoms of stroke and action to be taken when signs occur, determinants of high-quality health care for stroke, and other appropriate information.
2. Developing or compiling recommendations for primary care physicians that address risk factors for stroke, appropriate screening for risk factors, early signs of stroke, and treatment strategies. This may include evaluating the effectiveness of risk screenings and diagnostic testing for use by primary care physicians as a stroke prevention measure.
3. Developing or compiling for physicians, emergency health care providers and other health care providers, recommendations on initial and long-term treatment of stroke.
4. Developing or compiling for physicians, long-term care providers and rehabilitation providers recommendations on rehabilitation of stroke patients.
5. Assisting PADOH in the development of comprehensive plans regarding stroke and related health issues.
6. Assisting PADOH in administering the stroke registry.
7. Assisting PADOH in awarding grants related to the purposes of the act.
8. Taking other action to ensure that the public and health care providers are informed regarding the most effective strategies for stroke prevention and treatment.
9. Assisting the stroke office in preparing a report and prescribing recommendations for the governor, the department, and the legislature. After the report is issued, the council would meet annually and may meet at other times at the call of the chair to continue to advise the office.

The department is charged with publicizing the council's information and disseminating its recommendations as appropriate. Provisions relating to awarding of grants and the establishment of a stroke registry have been included. Precedent for creating a special office for dealing with a single condition exists in the Pennsylvania Cancer Control, Prevention and Research Advisory Board. The board consists of twelve members and

develops the Pennsylvania Cancer Plan for cancer control, prevention, and research. The board may recommend grants and contracts for a cancer registry; screening, detection and prevention; epidemiological and statistical studies; community outreach programs; rehabilitation; communication and planning among cancer institutions; education and information; training; and clinical research. The proposed statute draws from the Emergency Medical Services Act⁸⁰ the concept of a council that, like the State Advisory Council for EMS, consists mostly of representatives of private volunteer professional and paraprofessional organizations.

Representatives from seven public departments and agencies centrally concerned with the Commonwealth's response to stroke are also included on the council. This assures that the council will afford the office and the department advice from a broad array of stakeholders.

General Powers

- Establish a stroke information clearinghouse to collect and disseminate stroke research and information, including best practices relating to prevention, care and rehabilitation.
- Establish a stroke patient registry to assist medical research into prevention and treatment.
- Administer a program to award grants and contracts to private and public entities in support of programs in stroke prevention, care, education, training, and clinical research.

Prevention

- Support existing efforts to provide resources to local consortia where they exist and direct assistance to organizations where regional coordination is less advanced.
- Encourage and establish education programs to raise health care provider and public awareness of risk factors for stroke, particularly hypertension, diabetes, smoking, high cholesterol, and obesity.
- Encourage and establish public education programs to publicize the warning signs of stroke and the proper response to a stroke emergency.
- Ensure that public education programs are culturally appropriate to the groups at whom they are directed.
- Assist in developing and disseminating protocols to reduce the risk of suffering a stroke while under treatment for another condition and to guide acute care for such strokes.
- Conduct a study of the adequacy of insurance coverage for diagnostic services and preventive care, including the issue of whether or not mandatory coverage would be feasible.
- Conduct population-based research to improve the effectiveness of educational programs, especially targeting populations that are underserved because of geographic, socioeconomic, educational or cultural factors.

Acute Care

- Inventory all hospitals in the Commonwealth to assess whether all the resources necessary for hospitals to diagnose and initiate effective stroke treatment are available and accessible to all residents of the Commonwealth within one hour's time.
- Compile an official record of the stroke treatment capabilities of providers who self-designate or who undergo voluntary independent certification by an appropriate certifying organization and disseminate this information to EMS providers and other interested persons and organizations.

- Use the grant program to fund regional cooperative arrangements to promote improved stroke care at the regional level.

Rehabilitation

- Adopt or develop a statement of best practices for maintaining continuity of care between hospitalization and rehabilitation.
- Conduct a study of the appropriateness of the levels of care for stroke rehabilitation.
- Conduct a study of the cost-effectiveness of stroke rehabilitation, including the effect of early initiation of rehab.
- Assess rehabilitation coverage by health insurance plans and the comparative impact on care of differing standards of coverage as a basis for determining how effective the treatment under such plans is for survivors of stroke.
- Disseminate evidence-based guidelines and protocols relating to all phases of rehabilitative care.

APPENDIX 9

State Snapshots 2005

FROM THE
National Healthcare Quality Report



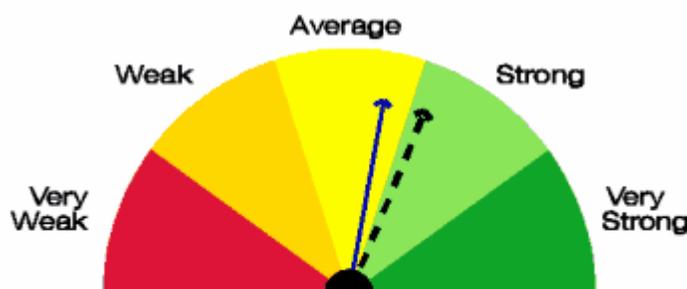
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Snapshot
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[All State Data Table](#)
[Regional Data Table](#)
[Setting of Care State Rankings for Selected Measures](#)
[Focus on Diabetes All-State Data Table for All Measures Methods](#)

What Is Delaware's Chronic Health Care Quality Performance Compared to All States and How Has it Changed?

The State's chronic care performance across all NHQR Quality Measures (up to 44) is shown below *compared to all States* in the **most recent data year (solid line)** and in a **preceding data year (dashed line)**.

My State Compared to:
[All States](#)
[South Atlantic States](#)



Performance Meter:
Chronic Care Measures

An arrow pointing to "very weak" means all or nearly all included measures for a State are [worse than average](#) within a given data year. Conversely, an arrow pointing to "very strong" indicates that all or nearly all available measures for a State are [better than average](#) within a given data year. The other categories scale from weak to strong performance and represent the State's balance of [worse than average](#), [average](#), and [better than average](#) measures. To examine all the measures behind this performance, click on the meter. For more information on how these measures are translated into a performance meter, select [Methods](#), or to view additional information about this State, make a selection from the menu on the left.

[D]