

Advancing the STOP Stroke Act in the 108th Congress

January 24, 2003

Core Principles

The STOP Stroke Coalition was asked to identify key priorities for legislation to improve the quality of stroke care. The legislation will be developed and advanced during the 108th Congress. This task was especially challenging given the number of barriers that ultimately need to be removed to ensure patient access to quality stroke care. Stroke care is best addressed along a continuum of care, which includes stroke prevention (primary and secondary), diagnosis, treatment and rehabilitation.

The Coalition strongly supported legislation in the 107th Congress to improve stroke care. The legislation – the STOP Stroke Act – was introduced by Senators Edward Kennedy and Bill Frist and Representatives Chip Pickering and Lois Capps. The STOP Stroke Act (S. 1274/H.R. 3431) would have authorized four new programs: a state grant program to help states ensure that all patients have access to quality stroke care; a national public awareness campaign to educate the public about the stroke warning signs and how stroke can be prevented; a registry and clearinghouse to collect data and share best practices; and a grant program to educate medical professionals in newly developed diagnostic approaches, technologies and therapies.

The Coalition agrees that stroke legislation advanced in the 108th Congress should contain at least the following two critical and complimentary provisions: (1) a grant program to help states improve the continuum of stroke care through the identification of Stroke Centers and the development of support networks and (2) a registry/clearinghouse to collect data on best practices and share outcomes of these efforts. Efforts to improve the quality of care under the grant program will be enhanced through the data acquired by the registry/clearinghouse.

STATE GRANT PROGRAM

Policy Description

The purpose of the grant program is to help States strengthen the continuum of stroke care (this includes stroke prevention, diagnosis, treatment and rehabilitation) through the identification of Stroke Centers and the development of support networks to facilitate effective communication, transportation and coordination of the care of stroke patients. The Coalition recommends that States have considerable flexibility to design and implement targeted, tailored plans to improve stroke care. This is necessary because care systems vary on a regional and local basis. Systems that may be appropriate in metropolitan areas may be inappropriate in rural areas. A State plan should include the following elements:

- Identification of Stroke Centers

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- Development and implementation of support networks
- Coordination with EMS/Training of EMS personnel
- Public awareness
- Development or enhancement of existing stroke prevention programs
- Medical professional development

While states should be given great flexibility in implementing a plan to improve stroke care, the Coalition recommends that states be required to use grant funds to identify Stroke Centers, to coordinate with EMS and to develop a support network to facilitate stroke care. States could also apply to use grant funds for public awareness, medical professional development and other purposes as permitted by the legislation. States should consider and incorporate best practices developed by the registry/clearinghouse (see below).

Policy Rationale

The proposed State grant program described above represents a more targeted effort than the grant program contained in the legislation advanced during the 107th Congress (S. 1274/H.R. 3431). It is also less prescriptive, providing States with greater flexibility to develop and implement a plan to improve stroke care. Rather than mandating that States pursue all of these activities, it is the Coalition's recommendation that the grant program focus on helping states establish core elements (identification of Stroke Centers, development of a support network and coordination with EMS).

S. 1274/H.R. 3431 would have created a separate national public awareness program in addition to a grant program to educate medical professionals about newly developed stroke therapies. The Coalition recommends folding these programs into the state grant program. For States that have already demonstrated progress in the core areas, the grant program could provide an opportunity to implement public awareness programs, stroke prevention programs or programs to educate medical professionals about newly developed stroke therapies.

Identification of Stroke Centers

The development and identification of Stroke Centers is an essential component for ensuring access to quality stroke prevention, treatment and rehabilitation. Strong support for this concept exists in the stroke community and resulted in the development of a consensus statement developed by the Brain Attack Coalition - a group of professional, voluntary and governmental entities¹ dedicated to reducing the occurrence, disability and death associated with stroke. The consensus statement, which was published in the Journal of the American Medical Association (June 2000), outlined the major elements of a Primary Stroke Center.

The purpose of identifying Stroke Centers/systems is to increase the capacity for all hospitals to provide quality stroke care, recognizing that levels of involvement will vary according to the resources and capabilities of hospitals, systems and states. All

¹ The Brain Attack Coalition includes the following government agencies: the National Institute of Neurological Disorders and Stroke (NINDS), the Centers for Disease Control and Prevention (CDC), the Department of Veterans Affairs (VA) and the Office of the Surgeon General.

hospitals that are capable of providing basic stroke services should be encouraged to participate. The expected outcome of stroke center identification is to increase the quality of patient care by assuring timely access to appropriate hospitals and professionals qualified in the management of stroke.

Identification of Stroke Centers should include an evaluation component to monitor clinical outcomes and procedures and verify the resources, infrastructure and operations devoted to stroke. Stroke Centers should be established based on the latest science and where available, a nationally recognized identification program should be pursued.

Development and Implementation of Support Networks

All hospitals in a system providing care to stroke patients have a significant role to play. States should develop and implement a plan to establish support networks to provide assistance to facilities with smaller populations of stroke patients or less advanced onsite stroke treatment resources. This plan could include support services such as telemedicine to help manage stroke patients or transportation of stroke patients to identified Stroke Centers, as appropriate.

Coordination with EMS/Training of EMS Personnel

Acute stroke management begins in the pre-hospital setting. One of the most significant barriers to the treatment of acute stroke patients is delay in presentation. An EMS system that is designed to rapidly transport patients to appropriate hospitals will increase the number of patients who receive appropriate emergency treatment. Protocols for patient transfer should be developed based on individual hospitals' diagnostic and therapeutic capabilities as well as a given patient's treatment preferences.

Recognition of stroke signs and symptoms by EMS personnel is critical. Several studies have demonstrated that EMS personnel are not adequately trained to recognize stroke patients. Research also shows that dramatic improvements can be made with modest training and better coordination of EMS services. For example, prior to training, San Francisco Fire Department paramedics correctly identified 61 percent of acute stroke victims. After a four-hour training program, paramedics were able to correctly identify 91 percent of acute stroke victims.

Public Awareness

The treatment window for acute ischemic stroke can be as short as three hours from the onset of stroke symptoms. Unfortunately, stroke patients and witnesses frequently wait as long as 22 hours before seeking medical care. Prompt recognition of the symptoms of stroke by patients and witnesses as well as awareness that stroke is an urgent medical emergency is key to reducing pre-hospital delays and allowing more patients to receive treatment within the three-hour therapeutic window. Even if the EMS system and hospital personnel are adequately prepared to provide timely and effective stroke treatment, patient delay in recognizing the warning signs and seeking treatment limits the effectiveness of the effort.

Prevention Programs

While it is critical that systems be established to ensure patient access to quality stroke care, it is also necessary to strengthen efforts to prevent stroke. The best way to prevent a stroke is to reduce controllable risk factors, which include (but are not limited

to) the following: high blood pressure, tobacco use, high cholesterol levels, obesity and physical inactivity. It is also important for public education efforts to focus on stroke prevention.

Professional Development

The gap between the science related to stroke treatment and practice is currently very large. Although the grant program will help states close this gap through the identification of Stroke Centers and the establishment of support networks, it is also essential to ensure that as new knowledge and information becomes available, it is readily translated into practice. Medical personnel and other appropriate health professionals should be trained on an ongoing basis in newly developed diagnostic approaches, technologies and therapies for stroke prevention, treatment and rehabilitation.

COVERDELL STROKE REGISTRY AND CLEARINGHOUSE

Policy Description

In addition to the state grant program, the Coalition recommends that stroke legislation developed and advanced during the 108th Congress direct the Secretary of the Department of Health and Human Services to maintain the Paul Coverdell Acute Stroke Registry and develop a clearinghouse to collect and share best practices with States, organizations and individual researchers. States that receive funding under the grant program should participate in the Coverdell Stroke Registry and share information with the Stroke Clearinghouse. In addition, States should consider and incorporate the best practices developed by the registry/clearinghouse to inform efforts to improve stroke care.

Policy Rationale

Coverdell Stroke Registry

During Fiscal Year 2001, Congress provided the Centers for Disease Control and Prevention with a limited amount of funding to establish the Paul Coverdell Acute Stroke Registry. The purpose of the registry was to design and pilot test prototypes that will measure the delivery of care to patients with acute stroke to provide real-time data for analysis. After the data points were established, the registry was rolled out in four states and has since expanded to eight states.

It is critical that States that receive funding under the grant program also participate in the Coverdell Registry. States should be encouraged to collect data from each facility that provides stroke care in the State. The data that is collected should – at a minimum – be consistent with the data points identified by the existing Paul Coverdell Acute Stroke Registry, which is managed by the Centers for Disease Control and Prevention (CDC). This activity will ensure some level of consistency across States and will help serve as the basis for evaluating the success of the grant program as well as identifying and sharing best practices in stroke prevention, diagnosis, treatment and rehabilitation. The Registry will also help facilitate quality improvement efforts in stroke management. The Secretary should consult with the stroke community to ensure that appropriate data points for all forms of stroke are collected.

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Stroke Clearinghouse

The clearinghouse will serve as a resource for States by collecting, compiling and disseminating information on the achievements and challenges experienced by State and local agencies as well as private entities in developing and implementing plans to improve stroke care. The clearinghouse will also help serve as a catalyst for sharing information among agencies, organizations and individuals.

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