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Translating Evidence Into Practice: A Decade of Efforts by the American Heart Association/American Stroke Association to Reduce Death and Disability Due to Stroke: A Presidential Advisory From the American Heart Association/American Stroke Association

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AHA/ASA Presidential Advisory

Translating Evidence Into Practice: A Decade of Efforts by the American Heart Association/American Stroke Association to Reduce Death and Disability Due to Stroke

A Presidential Advisory From the American Heart Association/American Stroke Association

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The American Heart Association's (AHA) stated mission is "to build healthier lives, free of cardiovascular diseases and stroke." Consistent with that mission, the AHA set a strategic direction in 1998 to provide information and offer solutions for the prevention and treatment of cardiovascular diseases and stroke in people of all ages, with special emphasis on those at high risk. The identified goal was to reduce coronary heart disease, stroke, and risk by 25% by 2010, as measured by 4 key indicators: A reduction by 25% in deaths due to coronary heart disease and stroke, prevalence of smoking, hypercholesterolemia, physical inactivity, and uncontrolled hypertension, along with a zero growth rate of overweight or diabetic individuals in the US population.

To help achieve these goals as they related to stroke and to exemplify the organization's commitment to stroke, the AHA formed the American Stroke Association (ASA) in 1998. This article documents the milestones encountered in this decadelong journey from 1998 to the present and attempts to capture the critical success factors that enabled the ASA to play such a prominent leadership role in the fight against stroke. Although many other organizations were working alongside the ASA to accomplish these goals and made essential contributions in their own right, the purpose of the present report is to trace the path

pursued by the ASA (or the AHA through its support of the ASA) and review in this context its central role as the lead organizer, the convener of experts, the cited source of stroke facts and statistics, and the organization that defined the common language for translating the available stroke evidence into real-world practice.

The present report is organized according to 4 basic domains of translating evidence into practice: (1) generating basic science knowledge, (2) disseminating scientific findings, (3) convening experts for consensus, and (4) implementing guidelines into practice. It concludes with some of the strategic directions that the AHA or ASA (referred to in the remainder of this report as the ASA) will consider during the next decade to further reduce the burden of stroke, help ensure that stroke patients from all communities receive care of the highest quality, and lead to the best possible health outcomes for all patients. It is our hope that this may serve as an illustrative example or blueprint for other nonprofit, disease-focused advocacy organizations seeking to reshape the public health agenda to improve health outcomes.

Background: Stroke in the Late 1990s

Decades of scientific research in acute ischemic stroke therapy culminated in 1995 with the publication of the

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National Institute of Neurological Diseases and Stroke intravenous tissue plasminogen activator (tPA) study¹ and approval of intravenous tPA for use in acute ischemic stroke in 1996 by the US Food and Drug Administration. However, by 1998, it had become clear that despite incorporating thrombolysis for acute ischemic stroke in guidelines and scientific statements by the AHA/ASA,²,³ the American Academy of Neurology (AAN),⁴ and the American College of Chest Physicians,⁵ rates of intravenous tPA use remained below 3%,6,7 and barriers to wider adoption were numerous.

In addition to the gaps identified in primary prevention, stroke awareness, and acute stroke treatment and delivery, it became clear that many patients hospitalized with ischemic stroke and transient ischemic attack (TIA) were also not receiving additional evidence-based therapies to reduce post-stroke complications or improve control of risk factors. In 1998, 1 American was having a stroke every 53 seconds and dying of stroke every 3.3 minutes (based on annual stroke deaths of 158 4488).

The low rate of use of intravenous tPA and the high stroke mortality highlighted the fragmentation of service delivery that characterized acute stroke care in the 1990s. Public awareness of stroke signs and symptoms was inadequate, those at highest risk were often the least informed,9 emergency medical services (EMS) were ill-equipped to recognize or respond to acute stroke, and hospitals needed tools to help them develop and implement multidisciplinary acute stroke teams similar to those successfully deployed for acute myocardial infarction or trauma resuscitation.

Translating Evidence Into Practice

Founding of the ASA

After decades of supporting the scientific and educational efforts in stroke through the AHA Stroke Council, the International Stroke Conference, and the journal Stroke, the AHA founded the ASA in 1998 to function as the programmatic vehicle that would help drive the translation of advances in the science of stroke prevention, diagnosis, and treatment into policies, programs, and strategies that would facilitate their incorporation into clinical practices and behavior change. The ASA focused on reducing disability and death due to stroke through research, education, fund-raising, and advocacy.¹⁰ To accomplish the strategic impact goal of a 25% reduction in stroke mortality and risk, the ASA chose to focus on creating coordinated systems of care and influencing health policy to enact sweeping changes to stroke healthcare delivery. The ASA further supported education campaigns to help the public better understand stroke warning symptoms and approaches to prevent strokes, increased communication among healthcare professionals, and provided information to stroke survivors and their caregivers to enhance their recovery after stroke and improve their quality of life.

Generating Basic Science Knowledge

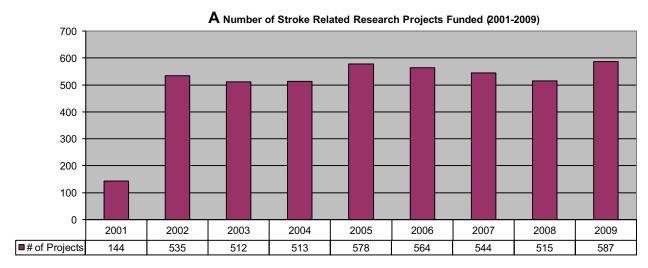
Advances in knowledge are essential to improvements in care. The ASA spends more money than any other organization except the federal government on stroke research and programs. Since 1949, the AHA/ASA has funded more than

\$3.1 billion of cardiovascular disease and stroke research. Furthermore, it has been a consistent and passionate advocate for federal funding of cardiovascular and stroke research, as well as programs at the National Institutes of Health and the Centers for Disease Control and Prevention (CDC).

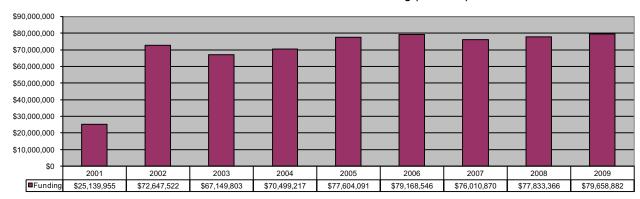
To further stroke research, the ASA funds basic clinical and population investigation in scientific areas related to stroke prevention, diagnosis, and other outcomes of treatment. These grants range from those provided to enhance the development of early career scientists via career development awards to those for senior investigators interested in outcomes research. Since 2001, more than 4400 stroke-related research grants have been funded (Figures 1A and 1B). During fiscal year 2005 to 2006 alone, the AHA/ASA spent almost \$157 million on strokerelated research, programs, and activities. Overall, the AHA/ASA allocates an average of 50% of their research dollars for projects related to stroke and partners with other organizations to amplify this impact. To help young investigators, the Council on Clinical Cardiology and the Stroke Council have provided a limited number of seed grants for young investigators for meritorious research projects based on the data gathered from Get With The Guidelines (GWTG). The ASA also partners with private organizations to fund research. For example, in 2006, the Bugher Foundation joined with the ASA to provide 4 years of support for 3 Stroke Prevention Research Centers with the goal of developing an interactive network¹¹ of institutions and scientists promoting collaborative, multidisciplinary research and training to improve the prevention of stroke. This network has come forth with and is now pursuing new collaborative goals in addition to the original research projects proposed.

Dissemination of Scientific Results

In the field of cardiovascular disease and stroke, ASA journals are among those with the highest impact. In addition to publishing key research findings, they serve as important vehicles for the diffusion of ASA scientific statements and guidelines. The journal Stroke was the first dedicated stroke publication for scientists, researchers, and clinicians and is considered by most to be a premier journal in the field. The annual International Stroke Conference has grown consistently over the past decade to represent more than 3500 healthcare professionals gathered to share the latest emerging science in the prevention, diagnosis, and treatment of stroke (Figure 1C). In addition to the International Stroke Conference, the ASA also disseminates research using satellite broadcasts viewed live by 4000 to 8000 healthcare professionals at a time through satellite TV networks in hospitals across the United States and by thousands of additional healthcare professionals via CD-ROMs, videocassettes, or audiocassettes distributed after each broadcast. The ASA's World Wide Web site¹² is one of the top-visited Web sites for the AHA, with more than 916 000 unique visitors, and contains a number of tools and resources targeted at multiple audiences, including healthcare professionals, stroke survivors, and family members.



B Stroke Related Research Funding (2001-2009)



C ISC Professional Attendance (2001-2008)

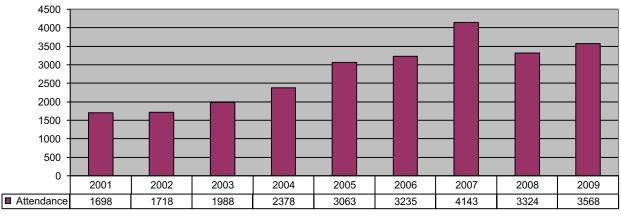


Figure 1. Temporal trends in stroke-related research projects, research funding, and International Stroke Conference (ISC) attendance.

Convening Experts for Consensus-Based Guidelines and Policies

The ASA has a long tradition of convening organizations, individuals, and advocates to generate consensus opinions on scientific data, clinical recommendations, or policy positions. Strategic partnerships have been essential to the ASA's ability to create the models for stroke center design, align stroke performance measurement, and achieve national endorsement of stroke quality indicators, to name only a few.

Some of these relationships are explored in more detail throughout this report.

Clinical Guidelines and Statements

Through its guideline writing committee structure under the auspices of the Stroke Council, the ASA has emerged as a leader in scientific guideline dissemination related to stroke. Using scientific research as the basis for its overall efforts, the ASA develops, maintains, and distributes comprehensive evidence-based practice recommendations to guide health professionals in stroke prevention and treatment and optimal poststroke recovery. ^{13–18} In addition, it partners with organizations like the AAN, ⁴ American College of Cardiology, ¹⁹ Department of Veterans Affairs, ²⁰ and American College of Chest Physicians ⁵ to align recommendations where overlaps exist.

Performance Measurement

There is increasing recognition of the power of performance measurement and financial or other incentives to improve care. The AHA/ASA worked to develop programs that recognize physicians who provide high-quality patient care through collaboration with the National Committee for Quality Assurance. This strategic collaboration led to the Heart and Stroke Recognition Program in 2003, with more than 2200 participating physicians.²¹ This voluntary program emphasizes the use of evidence-based vascular prevention measures and recognizes participating physicians who provide high-quality care for patients with cardiovascular disease and stroke.

In November 2003, the ASA served as the scientific advisor to The Joint Commission (TJC) to develop a national disease-specific primary stroke center certification program based on the Brain Attack Coalition (BAC) recommendations.²² The primary stroke center certification program was the TJC's first advanced-level, disease-specific certification program aimed at identifying centers dedicated to achieving better outcomes for stroke care.²³ This included monitoring of 4 required and 6 optional quality measures and was initiated in October 2004. A 12-month pilot study assessed the data reliability and collection burden, defined the measurement set and specifications, and identified potential measure modifications.

At the time, many hospitals were participating in more than 1 stroke quality-improvement program, including the ASA's GWTG-Stroke, the CDC's Paul Coverdell National Acute Stroke Registry (PCNASR), and TJC's primary stroke center program. The 3 programs were collecting and reporting similar but nonidentical elements and measures, and there were substantive differences that greatly increased the burden of collection for hospitals. In May 2006, the ASA led a consensus effort with the CDC and TJC to align the set of data elements and measures.²⁴ A harmonized set of 10 performance measures for stroke care was released effective January 1, 2008.

In an effort to gain wider national adoption of these consensus measures, these measures were submitted in February 2008 to the National Quality Forum for endorsement. Eight of the 10 measures proposed were endorsed by the National Quality Forum and subsequently introduced into the TJC core measurement set for hospital accreditation. Owing in part to the ASA's efforts, the Centers for Medicare and Medicaid Services (CMS) recently published its intention to assess hospital participation in a systematic clinical database registry for stroke care effective for fiscal year 2010 and to include the 8 National Quality Forum–endorsed stroke measures for fiscal year 2012 payment under the "Reporting Hospital Quality Data for Annual Payment Update" for the inpatient

prospective payment system. In addition, the ASA worked successfully with the CMS to replace the prior "Physician Quality Reporting Initiative" tPA measure with the new consensus-based tPA-administered measure effective in 2010

Collaborative Education Campaigns

A lack of collaboration between emergency physicians and vascular neurologists was identified as a key barrier to implementation of acute stroke therapy. The Stroke Collaborative Campaign was developed with the AAN and the American College of Emergency Physicians to address this. The "Give Me 5 for Stroke" educational campaign included educational tools for patients and providers to improve stroke recognition, assessment, and diagnosis, as well as consumer outreach materials. Two patienteducation documents bearing the logos of all 3 organizations address the risks and benefits of tPA, as well as what may occur in the emergency department, for patients who are diagnosed with a stroke or TIA. To date, more than 1.3 million support materials (eg, pins, posters, magnets, patient education materials, and physician resources) have been requested and/or distributed. A survey in November 2008 revealed that among responding emergency physicians and nurses, 87% intend to use the TIA document, 78% intend to use the tPA education sheet, and 84% believe that collaboration among the 3 organizations brings greater value to the campaign and education materials. The consumer outreach campaign on warning signs ("call 9-1-1" and "get to the ER fast") debuted in March 2008 and resulted in more than 200 million media impressions. The World Wide Web site (http://giveme5forstroke.org) displays the linkage of the 3 organizations; as of September 2008, the site has had more than 37 000 visits and 94 000 page views.

Implementation of Guidelines

By 1998, it had become evident that the mere publication of expert guidelines and practice recommendations was insufficient to change provider and patient behavior. A key part of the ASA strategy focused on identifying barriers to implementation of guidelines and fostering solutions.

Understanding the Barriers of Implementation

From the start, the ASA embarked on a series of consumer surveys to assess public awareness of stroke prevention, symptoms, and treatment as a first step in gauging the magnitude of the problem and as a tool for measuring the success of its educational initiatives. These surveys formed the basis for the subsequent highly visible Ad Council campaign and demonstrated the impact of sustained national advertising campaigns on public awareness and behavior.

Creating Infrastructure for Enhancing Care Delivery

The ASA has always been an active participant in the BAC, an umbrella advocacy organization that consists of professional, voluntary, and governmental entities dedicated to reducing the occurrence, disabilities, and death associated with stroke.²⁶ In 2000, the BAC published its *Recommendations for Establishment of Primary Stroke*

Centers,²² which delineated a series of principles and guidelines for the structure and operation of primary stroke centers. This BAC consensus standard was critical to the evolution of public health policy that supported the formation of stroke centers and the preferential rerouting of patients to qualified centers. In 2005, the BAC published a second paper entitled *Recommendations for Comprehensive Stroke Centers*,²⁷ which provided evidence- and consensus-based guidance to healthcare professionals, hospitals, and administrators for the development of comprehensive stroke centers.

In response to the lack of local and regional stroke infrastructure to support thrombolysis and primary stroke center development, one of the first initiatives of the ASA was the Metro Stroke Task Force (MSTF) program. The MSTF gathered healthcare professionals, allied health providers, civic leaders, and representatives of community organizations in 5 selected cities and tasked them with the following goals: To increase knowledge and awareness of the signs and symptoms of stroke; to improve capacity and response of the healthcare system for stroke; to expand access to care for those at risk and those experiencing stroke; and to promote awareness of the need to adopt healthy lifestyles to prevent stroke. The first-year impact of the MSTF program was assessed through a comparison of citywide surveys performed at baseline and 1 year after MSTF implementation.²⁸ All cities increased the implementation of hospital and prehospital stroke teams and protocols needed to assess and treat stroke patients. The MSTF program expanded to 15 additional cities, and the success and experience gained from MSTF was incorporated into the design of its successor, Operation Stroke, in 1999. Operation Stroke shifted the strategy away from individual silos of excellence and toward mobilization of the community for system change to improve the chain of stroke survival. The goal was to increase awareness of the chain's 4 links, (ie, rapid recognition and reaction to stroke warning signs; initiation of prehospital care; EMS system transport and hospital prenotification; and diagnosis and treatment at the hospital) and to strengthen the bonds between them.

From 2000 to 2004, Operation Stroke was implemented in 109 metropolitan areas. It began with stroke screenings attended by more than 600 000 individuals, as well as sponsorship of more than 100 continuing medical education events for health professionals. With awareness on the rise, in 2004, Operation Stroke shifted its focus to building hospital infrastructure per BAC recommendations. Operation Stroke extended its reach to approximately 1500 hospitals (nearly one third of all acute care hospitals in the United States), and by the end of fiscal year 2004, 558 hospitals met all 12 BAC recommendations, up from just 219 hospitals earlier that year.

Implementing Stroke Systems of Care

While centers of excellence and pockets of innovation were developing under Operation Stroke, an integrated, comprehensive approach to stroke care was just emerging. In 2005, the ASA released *Recommendations for the Establishment of Stroke Systems of Care*, ²⁹ which de-

scribed the fragmentation of stroke care and endorsed the shift to advocating for systems change and public policy adoption to create enduring systems of care that could address the entire continuum and the linkages between each domain from prevention through recovery. This coordinated stroke system-of-care model refined the prior chain-of-stroke-survival concept and expanded the scope to include 7 key components: Primary and primordial prevention; community education; notification and response of EMS; acute treatment for stroke; subacute stroke care and secondary prevention; rehabilitation and recovery; and continuous quality improvement of both the component domains and the whole stroke systems of care model itself. As is noted in "Programs and Processes: Illustrative Examples of Stroke System Development" below, GWTG-Stroke was one means used to further stroke systems of care by providing hospitals the tools needed to promote continuous quality improvement efforts.

The critical addition of continuous quality improvement signified a change in the organizational approach within the ASA. This unifying document aligned the internal goals of the ASA with its state advocacy initiatives, to identify gaps in current healthcare delivery systems. Ultimately, this approach led to an internal reorganization within the AHA that reintegrated ASA back into the organization's core activities. Although there continue to be dedicated activities and staff unique to the ASA, access to the skills and resources of the entire AHA organization has allowed the ASA to extend its reach and increase its impact.

Advocacy

Federal Advocacy

The gaps in the organization of stroke care nationwide highlighted the need for action at the federal level to enact and fund efforts to facilitate access to quality stroke care. The ASA helped develop and pushed to enact the Stroke Treatment and Ongoing Prevention (STOP Stroke) Act, first introduced in 2003. The aims of this legislation were to (1) fund a national information campaign to educate the public about stroke, including prevention, recognition of warning signs, and response; (2) create a grant program to states to foster the development of coordinated, statewide stroke care systems; (3) create a clearinghouse to provide technical assistance to states and share best practices; and (4) support stroke-related training for healthcare providers. Unfortunately, despite strong bipartisan support, efforts to enact the STOP Stroke legislation were unsuccessful, and the bill is unlikely to be reconsidered in the near future. Given the lack of success with the STOP Stroke Act, the ASA shifted its focus to advocate for local and state efforts to implement the kinds of policy change envisioned within the STOP Stroke Act and outlined in the stroke systems of care model. In addition, the ASA continues to try to protect Medicare stroke patients from arbitrary limits on outpatient therapy services through its support of the Medicare Access to Rehabilitation Services Act of 2009 (Senate Bill 46/House Resolution 43),30 which would permanently repeal these financial caps.

State Advocacy

The ASA engaged in a number of activities aimed at fostering the development of stroke systems of care, including the creation of state stroke advisory taskforces and implementation of state-based stroke center certification programs, many of which included mandatory data reporting for compliance.31 Consistent with national goals, ASA regional staff played a central role in these efforts to promote stroke systems and improve quality of care locally and regionally. Many regions and states established stakeholder groups to review the elements of the stroke system of care in their communities and identify gaps. These committees included EMS providers, emergency physicians and emergency medicine nurses, stroke center leaders, rehabilitation specialists, patient educators, and Departments of Health staff. A summary of some representative state legislative and regulatory activities can be found in the Appendix.

Grassroots Community Organization

The ASA also developed a national network in 2005 to organize grassroots advocacy for public policies at the local, state, and federal levels. Currently, through the "You're the Cure" network, 175 000 ASA volunteers advocate for vital funding for research and prevention, ways to prevent obesity (eg, improved quality of physical education and nutrition in schools), tobacco control (eg, smoke-free public areas), and greater access to stroke treatment and prevention.

Measuring Progress and Setting Goals

Through an integrated approach with state health departments and stakeholder organizations, the ASA promotes efforts to create coordinated statewide systems of care to improve the treatment of stroke patients in 5 key domains. These include the following: (1) working to ensure the recognition of primary stroke centers based on TJC certification or an equivalent process; (2) utilizing current ASA guidelines for stroke care to promote statewide standardization and implementation of the EMS system for stroke training, assessment, treatment, and transportation protocols; (3) supporting the utilization of telemedicine to extend stroke treatment expertise to underserved areas; (4) encouraging the removal of barriers for rehabilitation referral and treatment of stroke patients; and (5) increasing public recognition of stroke prevention and symptoms, as well as the need for early emergency intervention for acute stroke.

To further these objectives, the ASA has established a formal committee of volunteers to develop metrics to evaluate progress in achieving these stroke systems milestones. Through the analysis of these progress measures, the ASA identifies gaps in care, increases attention to neurologically underserved areas, and creates messages to raise public awareness. Through the use of new tools such as geospatial information and geographic information system mapping, these progress marker efforts will enable a comprehensive assessment by 2010 of the stroke systems capacity in all 50 states. Markers include (1) the presence of coordinated triage systems between EMS and those hospitals with stroke treatment capabilities; (2) 100% population coverage with 9-1-1;

(3) the percentage of EMS providers using a nationally recognized stroke assessment or scale; and (4) the percentage of hospitals participating in an acute-stroke quality-improvement registry or data-collection effort (Figure 2).

As of January 2009, there were more than 541 TJC-certified primary stroke centers, 200 state-designated stroke centers, and 1330 GWTG-Stroke participating hospitals. Among these, 546 hospitals have received a GWTG performance achievement award for maintaining at least 85% compliance on each of the 7 GWTG-Stroke achievement measures (http://www.americanheart.org/presenter.jhtml?identifier=3022006) for a specified duration, with 156 bronze (90 consecutive days), 193 silver (12 consecutive months), and 197 gold (≥24 consecutive months) hospitals.³²

More than 80% of the US population (250 million residents) now lives within a 60-minute drive of a TJCcertified primary stroke center or state-designated stroke center, and 68.2% (211 million residents) lives within a 30-minute drive. Regionally, in 14 states, more than 90% of the population lives within a 60-minute drive of a TJC-certified primary stroke center or state-designated stroke center, and 86% lives within a 60-minute drive of a GWTG-Stroke award-winning hospital; in 8 states and Washington, DC, every resident lives within a 60-minute drive of a TJC-certified primary stroke center or GWTG-Stroke award-winning hospital. In 33 states and Washington, DC, 90% of the population has enhanced 9-1-1 coverage for landlines. All 50 states have a state hospital system map, state stroke stakeholder committee, and stroke awareness campaign and have included stroke on their state health policy agenda. This revolutionary transformation in the organization of acute stroke care delivery was accomplished in a relatively short period of time and lays the foundation for the additional components necessary to implement the architecture required to address the complete continuum of care.

Programs and Processes: Illustrative Examples of Stroke System Development

The following section highlights efforts by the ASA aimed at developing or implementing programs within each of the stroke systems of care components. Although a substantial proportion of the effort was aimed at acute treatment and hospital-based care, considerable prevention and recovery efforts were already under way.

Primary and Secondary Prevention

The ASA, along with partner organizations, recognizes and values the importance of programs that focus on risk factor recognition and management and the prevention of cardio-vascular disease and stroke through a number of programs, including guidelines/statements, cause initiatives, and public education.

Stroke Awareness and Risk Reduction

In addition to programs and products focused on educating and providing resources to the healthcare professional, the ASA realized the importance of awareness of stroke signs and symptoms in patients and their families and friends, so that

Stroke Systems of Care - Hospitals

USA: Total Population by County

30 & 60 Minute Drive Time from Primary Stroke Centers

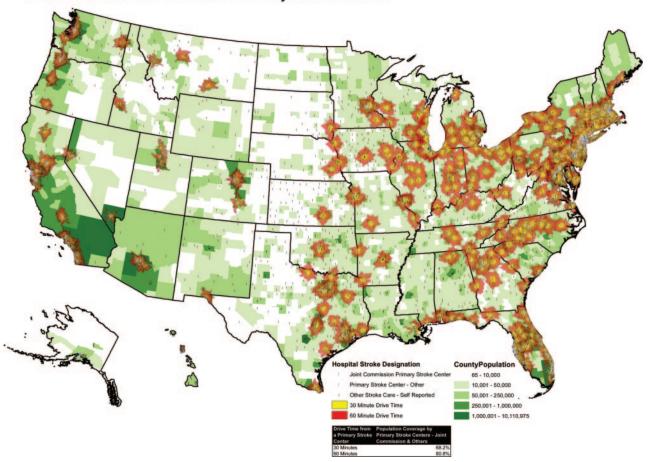


Figure 2. Geospatial Information Systems (GIS) map displaying TJC primary stroke centers and state-certified or other stroke centers and the distance to the nearest TJC primary stroke center for the US population by county. Source: ESRI 2007. Joint Commission Primary Stroke Centers and State-Designated Stroke Centers as publicly reported on 1/1/09.

they could become more engaged in their health lifestyle choices and health care. In 2003, the ASA, in partnership with the Ad Council, launched a public service campaign through public service announcements aimed at improving immediate stroke recognition and response by encouraging individuals to dial 9-1-1 at the first sign of a stroke.33,34 In an initial 2005 national tracking survey that the ASA and the Ad Council instituted, the majority of respondents already were very or somewhat confident that they could recognize the signs of a stroke and get to a hospital immediately if they or someone else were having one (unpublished data, Stroke Awareness Campaign: Tracking Survey Report, Ad Council and American Stroke Association, March 2005). Only 60% of respondents, however, said they would call 9-1-1 immediately. By 2008, this proportion increased to 71% (unpublished data, Stroke Awareness Campaign: Tracking Survey Report, Ad Council and American Stroke Association, April 2008).

The ASA uses surveys to identify gaps in understanding or implementation and to design targeted efforts to improve awareness. Despite the successes, the ASA realized the need for continuous reinforcement of public education to maintain awareness of the signs and symptoms of stroke

and address risk factor reduction. Together with partner organizations, the ASA advocates for measures to reduce tobacco consumption and the effects of passive exposure to tobacco smoke and distributes multilingual provider and public education materials to improve control of blood pressure and cholesterol³⁷ and to improve diet and nutrition.³⁸ To raise awareness among specific audiences, the ASA recognizes the need for more targeted campaigns focused on demographic groups, such as those at highest risk, to produce dramatic gains.

Cause-Based Initiatives

To address the needs of specific segments of the at-risk population, the AHA/ASA developed cause-based initiatives that integrate a social issue or cause into the organizational identity to achieve significant community impact and enable targeted fund-raising. The ASA has engaged in a number of cause campaigns aimed at stroke and risk factors. Despite the devastating impact of stroke on the black community, an ASA survey found that many blacks do not believe stroke will happen to them and have limited knowledge of stroke risk factors, signs, and symp-

toms (unpublished data, American Stroke Association National Survey, 2005).

Because of these knowledge gaps, the ASA developed the Power to End Stroke campaign (http://powertoendstroke.org) to educate blacks on the impact of hypertension, diabetes, and stroke and to empower individuals to (1) talk to a doctor, (2) exercise or walk, (3) undergo a stroke risk assessment, and (4) participate in a health screening. The Power to End Stroke campaign hopes to further engage partners, medical professionals, and policy makers to achieve these goals. To date, more than 400 000 individuals have joined Power to End Stroke. Stroke prevention and control messages are also included in other AHA cause campaigns, including Go Red for Women (designed to increase cardiovascular awareness among women), the Alliance for a Healthier Generation (with a targeted obesity reduction of 1.38 million kids), and Start! (with >50 000 individuals registered on http://startwalkingnow.org). Cumulatively, these programs have reached millions of people, and all of them show a positive impact on recognition of and progression toward healthier living choices.

Notification and Response of EMS

EMS Education and Training

Rapid recognition of stroke symptoms and appropriatepriority dispatch are critical to the deliverance of high-quality and timely stroke care. On behalf of the ASA, its Emergency Cardiovascular Care Division developed a number of tools for prehospital and hospital-based emergency cardiovascular care training and made them available at the eLearning library (www.onlineaha.org). Originally, the Advanced Cardiovascular Life Support (ACLS) program training for stroke consisted of 1 chapter within the AHA's ACLS-The Reference Textbook. In 2003, this resource was made available to a larger audience when it was adapted into an independent study activity, and in 2006, it became available online. In addition, the AHA/ASA continues to provide stroke training through its ACLS provider-training manual. In fiscal year 2008 alone, the AHA/ASA trained more than 800 000 providers and more than 55 000 instructors in ACLS.

Additionally, the AHA/ASA developed a course to improve prehospital decision making by strengthening the use of EMS triage and transport protocols and standardizing approaches to prehospital care. Stroke Prehospital Care Online covers pathophysiology, risk factors, differential diagnosis, recognition, assessment, and management. The course encompasses 4 interactive audio cases that include stroke-related patient encounters, prompts for participants to make management decisions, and an online test and evaluation.

Stroke EMS System Survey

In 2009, the ASA performed a nationwide survey that confirmed that significant progress had been made in the stroke care delivered by EMS systems. The ASA received responses from \approx 5410 (\approx 35%) of the 15 000 to 17 000 agencies interviewed, serving 91% of the US population. The survey revealed that \approx 50% of EMS responders complete at least 2 hours of stroke assessment education per year and that the majority of the systems in the United States use stroke

triage assessment tools (74%) and stroke treatment protocols (75%) consistent with AHA/ASA ACLS guidelines⁴⁰ to transport patients to designated stroke centers (62%) on the basis of approved triage algorithms. However, only 30% of agencies reported that they had a dispatch center that used established standards or protocols for emergency medical dispatch of stroke patients.

Acute Hospital-Based Stroke Care

Acute Stroke Treatment Program

Launched in 2000, the ASA's Acute Stroke Treatment Plan program⁴¹ was designed to guide hospitals through a step-by-step process for establishing a primary stroke center. The program was released on the same day as the BAC recommendation paper to ensure that healthcare professionals would have practical guidance on how to translate the scientific recommendations into practice. This reflected the new emphasis on guideline implementation that the ASA had embraced. The Acute Stroke Treatment Plan has been widely used by hospitals to help ensure that they deliver high-quality and efficient care to acute stroke patients and as a method for assisting with GWTG-Stroke implementation. The ASA supports this activity with collaborative regional workshops to help hospitals overcome inadequate infrastructure and other challenges when setting up a primary stroke center.

National Institutes of Health Stroke Scale Training Course and Certification

To encourage the use of the National Institutes of Health Stroke Scale, the ASA partnered with the AAN and the National Institute of Neurological Diseases and Stroke to develop a free, continuing medical education online certification and training program for healthcare professionals.⁴² The program (http://learn.heart.org) includes videotaped patient assessments with instant scoring, immediate feedback for incorrect responses, course completion certificates, and recognition for the partnering organizations. Since its launch in 2003, nearly 100 000 participants have been certified, and the site averages 5000 participants per month. It is the first ASA continuing medical education course that is available via mobile application.

Changing Stroke Reimbursement

Although intravenous tPA had been approved by the Food and Drug Administration for almost a decade, it was not until 2005 that the CMS considered covering the increased cost associated with its administration by creating a new diagnostic-related group. On the basis of input from the ASA, BAC, and AAN in fiscal year 2006, CMS created diagnostic-related group 559, which carries higher reimbursement for patients receiving thrombolysis (average of \$11 578) than for those who do not (\approx \$5000). Although the changes in the diagnostic-related group code did help improve access to tPA by reimbursing hospitals more appropriately, it did not account for those acute stroke patients in whom intravenous tPA is begun in an outside emergency department and who are then transferred to another hospital's stroke center ("drip and ship") for subsequent care. In 2008, the ASA and AAN met with CMS to discuss this concern, and as a result, an administrative code (or "V code") was approved to help gather evidence of use that will aid CMS in obtaining a more comprehensive picture of "drip and ship" frequency and distribution, as well as more specific data such as length of stay and average patient charges. Eventually, data derived from the V code will be used by CMS to determine whether modifications to the current tPA reimbursement system are warranted.

NorthEast Cerebrovascular Consortium

The NorthEast Cerebrovascular Consortium was established in 2006 and reflects a partnership between the ASA (its fiscal agent), stroke volunteers, advocacy organizations, public health officials, and policy makers in the 8 Northeastern states. Its goal is to develop an implementation plan specific to the Northeast that is based on the 2005 ASA stroke systems of care model framework to address regional disparities and recommend strategies to improve regional stroke care. Best practices and the disparities in evidence-based interventions within each Northeast state and within each of the stroke systems of care model components have been presented annually (http://thenecc.org), and significant variations in the delivery of stroke care and opportunities for improvement have been identified, particularly in urban versus rural areas. The findings and recommendations of these annual meetings were published in 2009 and represent the next iteration in system and policy change development by moving from the state to a regional impact level.43

Rehabilitation and Recovery

Beyond its efforts at improving acute stroke management through thrombolytic therapy, stroke centers of excellence, implementation of evidence-based guidelines, 44,45 and development of stroke registries and quality measures, the ASA has contributed to efforts to improve rehabilitation and recovery. Leadership at the level of the stroke council (eg, Nursing and Rehabilitation Professions Committee and Rehabilitation and Recovery Committee) and programming at the International Stroke Conference (eg, State of the Art Stroke Nursing Symposium) have focused on the needs and interests of the approximately 900 nurses and rehabilitation professionals who have attended the International Stroke Conference each of the past 8 years. In addition, the International Stroke Conference has added core program symposia focusing on rehabilitation and recovery and has increased opportunities for interaction at the Nursing and Rehabilitation Roundtable.

Continuous Quality Improvement

GWTG-Stroke: Teaching Hospitals to Improve, One Measure at a Time

On the basis of research findings generated from clinical investigation, those interventions supported by the highest level of evidence are used to formulate guidelines and scientific statements to help guide clinical care. 46 The ASA updates these guidelines and statements every 2 years to account for changes in science, with practice advisories issued if new research that would affect an existing recommendation becomes available in the interim. Given the evidence that traditional distribution of practice guide-

lines does little to change daily practice, the ASA developed an alternative method to facilitate the use of evidence-based guidelines through clinical decision support tools that aid healthcare professionals in making informed care decisions.^{5,19}

In 2001, the ASA began developing the GWTG-Stroke program, modeled after a similar successful program in coronary artery disease.⁴⁷ After a 2-year prototype phase funded in part by a PCNASR Prototype Grant from the CDC, the program was pilot tested in 2003 to determine whether GWTG-Stroke could provide hospitals with the tools needed to improve care for stroke patients. From April 2003 through March 2004, hospitals in selected regions of 8 states were invited to participate. Starting in April 2004, the program was made available to all US hospitals. The program sought to ensure that patients hospitalized with stroke and TIA were treated according to the latest evidence-based guidelines. Baseline and ongoing data collection, decision support, and hospital data feedback via multiple on-demand performance, quality, and demographic reporting measure reports are all key features of the GWTG-Stroke program.

The results during this initial phase of GWTG-Stroke were based on analysis of 18 410 patients from 99 hospitals and were published in 2008.⁴⁸ There was a rapid and marked improvement across all 7 measures during 1 year of participation. A more definitive analysis of the national rollout of GWTG-Stroke, published in 2009, showed that participation was associated with substantial improvements in the 7 individual and 1 composite measure of performance from baseline to a fifth year of participation (Figure 3).⁴⁹

Since its launch, almost 1330 participating hospitals have enrolled more than 1 million patient records. The ASA is continually working on ways to expand participation in GWTG-Stroke and to further improve its functionality and tools through the development of additional process and outcome measures based on new clinical science and guidelines, dissemination of stroke/TIA best practices, addition of personalized patient educational materials, interfaces with multiple electronic heath records systems, and links to the ambulatory care setting. In response to the growing concern over hospital readmissions and postdischarge adherence to prevention strategies, GWTG now incorporates a 30-day stroke follow-up form that is available to all hospitals. The follow-up form allows the capture of information relating to readmissions, mortality, medication use, risk factor control, use of rehabilitation services, and functional outcomes.

In addition, the ASA assisted the Duke Clinical Research Institute in the development and implementation of the Adherence eValuation After Ischemic Stroke Longitudinal (AVAIL) study,⁵⁰ a longitudinal assessment of the factors that promote patient adherence to risk reduction interventions after discharge from a GWTG-Stroke hospital. This design capitalizes on the infrastructure already in place within the GWTG-Stroke program to address new scientific questions of clinical effectiveness in real-world communities at a greatly reduced cost.

■ Baseline ■ YR1 ■ YR2 ■ YR3 ■ YR4 ■ YR5

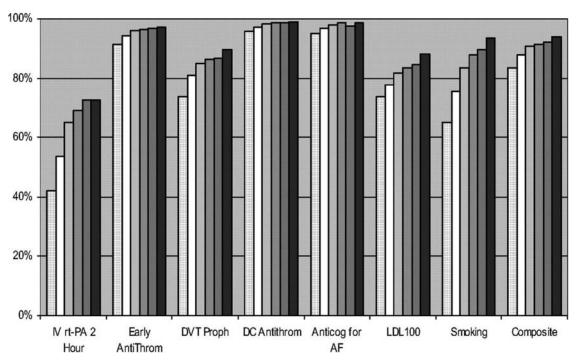


Figure 3. Improvement over time in GWTG-Stroke participating hospitals, displayed as the percentage of eligible patients who received each evidence-based measure per program year for the 7 individual measures and a composite measure of performance. YR indicates year; IV rt-PA 2 hour, intravenous recombinant tissue plasminogen activator given within 2 hours; Early AntiThrom, early antithrombotic; DVT Proph, deep vein thrombosis prophylaxis; DC Antithrom, discharged on antithrombotic; Anticog for AF, anticoagulation for atrial fibrillation; and LDL 100, low-density lipoprotein ≥100 mg/dL. Reprinted from Schwamm et al,⁴⁹ with permission from Lippincott Williams & Wilkins. Copyright 2009, American Heart Association.

PCNASR Prototype

In 2000, Congress appropriated \$4.5 million for fiscal year 2001 to the CDC for the development of the PCNASR program, a national acute stroke registry to track and improve the delivery of care to stroke patients. Through its advocacy to support funding of the CDC's PCNASR and heart and stroke programs, its collaboration with the CDC on harmonization of stroke performance measurement, and the substantial number of states using GWTG-Stroke to report their PCNASR data, the ASA plays an important supporting role in the PCNASR. In addition, the PCNASR represents, in many states, a key strategic partnership between state departments of health, the ASA, stroke volunteers, and the CDC.

In 2005, a report entitled, "Acute stroke care in the US: results from 4 pilot prototypes of the Paul Coverdell National Acute Stroke Registry" served to describe the unsatisfactory reality on the grounds of the characteristics of acute stroke admissions and the in-hospital care received across the original sites. The findings suggested that fewer than 10% of acute stroke patients arrived at an emergency department within 1 hour of stroke onset, and fewer than 25% arrived within 3 hours. Additionally, documentation of time of onset of stroke symptoms occurred in only 33% to 50% of cases. Finally, only 3.0% to 8.5% of all ischemic stroke patients were treated with tPA. This information served as fodder to instigate major changes to the systems of care of stroke described above.

ASA Strategy to Reduce Death and Disability Due to Stroke: Is It Working?

According to 2007 preliminary mortality data from the National Center for Health Statistics, a 32.5% decline in stroke death rates occurred between 1999 and 2007.52 Other sources, including data from the National Center for Health Statistics, the National Health and Nutrition Examination Survey, and the National Health Interview Survey, confirm a steady decline over the past few years. Although many other factors and secular trends have surely contributed to this reduction in mortality, it seems reasonable to assume that the immense efforts by the ASA to increase patient awareness of stroke risk and warning signs and the need to activate 9-1-1 early, to improve hospital-based care and rates of adherence to evidence-based prevention strategies, and to increase access to rehabilitation services have also played a role in this steep decline in mortality and better health outcomes for stroke patients.

Stroke: The Next Decade

The ASA saw great success in the prior decade's emphasis on acute care delivery. Now the time has come for a greater focus on stroke prevention and recovery and for greater emphasis on global health initiatives and international partners. In 2009 alone, direct and indirect costs associated with the projected 800 000 strokes are anticipated to reach \$68.9 billion. The new strategic impact goal for the next

decade reflects this approach and articulates that, "By 2020, [the AHA/ASA will work] to improve the cardiovascular health of all Americans by 20% while reducing deaths from cardiovascular diseases and stroke by 20%."53 To reach the 2020 goal, the AHA/ASA will need to continue to be innovative in how health information is delivered (eg. interactive media, new care guidelines) and analyzed (eg, geospatial information and geographic information system mapping) and to attract even more hospitals to participate in its programs in the inpatient and outpatient settings, expand its influence in shaping public policy, continue to support advances in the clinical and basic sciences (eg, stroke rehabilitation and recovery), and expand programs to shift the population to states of ideal cardiovascular health. This will require new analytic tools, new audiences, and new volunteers.

In addition, the ASA needs to ensure that the unmet needs of stroke patients continue to be addressed at the federal, state, and community level. The assurance that rehabilitative care is considered an essential service covered by all health plans, without annual or lifetime limits, is an important issue for consideration under any healthcare reform. Health care must be expanded to the remainder of the US population, must be both affordable and of high quality, and must include access to preventative and rehabilitative services. The ASA should support healthcare reform that prioritizes cardiovascular health and facilitates a way of life that is free from stroke and heart disease for all citizens. There is an immediate need to develop scientific guidelines for stroke recovery and rehabilitation and for more integrated and innovative poststroke management programs, continuity of care records, and qualityof-care indicators for post-acute care.

GWTG-Stroke provides valuable data to characterize demographics, performance measures, and in-hospital clinical outcomes in a very broad cohort of acute stroke and TIA hospitalizations from every state in the country. There have been substantial improvements over time in performance measures and in-hospital clinical outcomes in stroke and TIA patients, but many opportunities remain to further improve care and outcomes. The value of GWTG-Stroke as an integrated stroke and TIA national registry that provides national surveillance, supports vigorous efforts to improve evidence-based stroke/TIA care and clinical outcomes, and fosters innovative research is now well established. The ASA, in partnership with TJC and the CDC, will strive to expand participation in GWTG-Stroke to every acute care hospital in the United States.

To further improve care in the ambulatory setting, the AHA/ASA has developed GWTG-Outpatient. Its vision for the program is to improve outcomes for patients with cardiovascular disease and stroke through widespread application of AHA/American College of Cardiology primary and secondary prevention guidelines in the United States through data collection, analysis, feedback, and quality improvement. To achieve this end, the ASA is working with electronic health record vendors to develop specifications to test compatibility that can be used by physician practices to improve the care of patients with cardiovascular disease and stroke.

Modest alterations in health behaviors can have a substantial effect on stroke risk and are the basis of population-wide and high-risk approaches to prevention. In addition to continued efforts to reduce established risk factors, local, state, and federal initiatives⁵⁴ that target modifiable lifestyle behaviors in the community at large can be an effective strategy to prevent or postpone stroke and to reduce its severity and impact.^{2,55,56} The focus of the next decade will be to shift individuals and communities to states of ideal cardiovascular health, which will translate into fewer strokes and help achieve the ASA's 2020 impact goal.

New data suggest that tPA can be administered safely and effectively to a broader population of stroke patients.⁵⁷ Regional systems of care offer the opportunity to expand the availability of systems-based approaches to acute stroke care and thrombolysis delivery freed from geographic and economic constraints. However, the shortage of available staff and resources (neurologists, neurosurgeons, and specialized nursing personnel) needed to treat acute stroke in the emergency and subacute phase will only accelerate in the coming decade. New methods are desperately needed to address these looming manpower shortages and increase the availability of key personnel at critical timepoints. Strategies such as telemedicine, air medical transport, continuing education, and as yet undiscovered means that link hospitals of differential capabilities within a larger stroke system of care need to be developed and expanded.

Conclusions

The ASA and its many partners spent the past decade methodically, thoughtfully, and effectively changing the care-delivery system for stroke in the United States. The efforts outlined in the present report should be considered a case study in system change; however, there is much more to do. The ASA's 2020 goal offers the stroke world the same opportunity for positive change in this decade that the 2010 goal offered in the last.

Over the past decade, the ASA has made a tremendous effort to meet the needs of the stroke community and the stroke patient. The majority of strokes are preventable, and it is the responsibility of an association such as the ASA to have a broad mission of prevention, treatment, and rehabilitation of stroke. We must continue to concentrate on generating the policies, programs, and services that can reduce the burden of stroke.

If past performance is an indication of future potential, we are embarking on another banner decade for stroke.

Finally, we take this opportunity to acknowledge the work of organizations such as the AAN, American College of Chest Physicians, American College of Emergency Physicians, BAC, CDC, National Committee for Quality Assurance, TJC, National Quality Forum, National Stroke Association, Department of Veterans Affairs, and the World Stroke Organization, as well as the many others who have worked side by side with the ASA during the past decade in the effort to reduce death and disability due to stroke.

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Appendix

Examples of State Efforts to Promote Stroke Systems and/or Registries

May 2010

State/Bill or Regulation	Description	Links* to State Bill or Regulation			
Delaware (DE 2008 HB 378)	Creates a statewide PSC designation program. Hospitals that want to be recognized by the state as a PSC must first be accredited as such using TJC's PSC program.	http://legis.delaware.gov/LIS/lis144.nsf/EngrossmentsforLookup/HB +378/\$file/Engross.html?open			
Georgia (GA 2008 SB549)	Creates a certification system for stroke-ready hospitals in Georgia. PSCs are certified by TJC, whereas remote treatment centers will be certified by the responsible agency. Mandates that EMS providers, subject to patient choice, deliver acute stroke patients to only those hospitals that have received stroke-facility certification.	http://www.legis.ga.gov/legis/2007_08/versions/sb549_AP_8.htm			
Illinois (HB2244)	The new law will require the state Department of Public Health to designate as many certified PSCs as apply for that designation, provided they are certified by a nationally recognized certifying body, approved by the department. Requires the Department of Public Health to designate hospitals as Emergent Stroke-Ready Hospitals capable of providing emergent stroke care.	http://www.ilga.gov/legislation/fulltext.asp?DocName=09600HB 2244enr&GA=96&SessionId=76&DocTypeId=HB&LegID= 44072&DocNum=2244&GAID=10&Session			
Maryland (COMAR 30.08.11)	The Maryland Institute for Emergency Medical Services Office of Hospital Programs has the authority to designate PSCs statewide (using TJC as the official entity for certification) and has statewide transport protocols that allow patients to bypass hospitals to go to a PSC.	http://www.dsd.state.md.us/comar/SubtitleSearch.aspx?search= 30.08.11.*			
Massachusetts (10 CMR 130.1400–1413)	The MA Department of Public Health regulations establish a designation process for Primary Stroke Service Hospitals. PSC requirements, as defined by the BAC, are embedded in Massachusetts' Primary Stroke Service designation process.	http://www.mass.gov/Eeohhs2/docs/dph/regs/105cmr130.pdf			
Missouri (HB 1790)	Department of Health and Senior Services to designate a hospital as a stroke center upon proper application and review. On-site facility reviews will occur every 5 years by the department, with the department solely responsible for establishing appropriate fees for review.	http://www.house.mo.gov/billtracking/bills081/biltxt/truly/HB1790T. HT M			
New York	New York State PSC legislation is primarily a function of regulation of EMS agencies. Divert appropriate stroke patients to a state-designated stroke center, but only if the patient can arrive at the designated center within 2 hours of the onset of stroke symptoms. EMS personnel to contact the stroke center to notify them of the transport.	http://www.health.state.ny.us/professionals/hospital_administrator, stroke_center_desigination/index.htm			
New Jersey (NJS477)	Outlines the requirements for both a PSC and a CSC, which are based on the standards recommended by the BAC. Directs the Commissioner of Health and Senior Services to designate hospitals as PSC or CSC if they apply to the Commissioner and meet the standards outlined in the Act. Establishes a grant program providing matching grants to hospitals seeking PSC or CSC designations up to \$250 000 or 50% of their development costs.	http://www.njleg.state.nj.us/2004/Bills/PL04/136HTM			
North Dakota (HB 1339)	Requires the Department of Health to designate qualified hospitals as PSCs (to take effect January 1, 2010). Hospitals must demonstrate that they meet requirements set by the Department (eg, TJC stroke certification). Stroke system task force was established and will set recommendations by April 1, 2010.	http://www.legis.nd.gov/assembly/61-2009/bill-text/JACl0300.pdf			
Oklahoma (OK 310 OAC 667)	Directs the State Department of Health to establish a statewide coordinated system of care for stroke. When developing their statewide stroke system of care, special focus and attention will be given to timely access to care, diagnosis, and the most advanced treatment for persons most disproportionately affected by stroke.	Senate Bill 1420: http://webserver1.lsb.state.ok.us/2007-08bills/ SB/SB1420_ENR.RTF (temporary rules) and http://www.okoha.com/AM/Template.cfm?Section=Quality_ Improvement1&Template=/CM/ContentDisplay.cfm&ContentID= 11494			
Tennessee (TN 2008-SB-4011)	Creates a comprehensive stroke registry using GWTG criteria. The registry will be housed in the East Tennessee State University College of Public Health.	http://wapp.capitol.tn.gov/apps/Billinfo/default.aspx?BillNumber= SB4011&ga=105			
Virginia (VA 2008 HB479)	Directs the Virginia Board of Health, in consultation with the ASA, to develop a Stroke Triage Plan designed to promote access to rapid care for stroke patients. The plan will recognize the importance of PSCs, as certified by TJC or a comparable process consistent with the recommendations of the BAC, as well as create a uniform set of criteria for prehospital and interhospital triage and transport of stroke patients.	http://leg1.state.va.us/cgi-bin/legp504.exe?081+cab+ SC10215HB0479+UCHB2			

PSC indicates primary stroke center; CSC, comprehensive stroke center.

^{*}The above links were active and functional when accessed on November 19, 2009.

Disclosures

Writing Group Disclosures

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Pamela Duncan	Duke	NIH/NINDS*	None	None	None	Health Care Profession Seminars—continuing education for physical therapists/occupational therapists*	Allergan*; GlaxoSmithKline*; Wyeth*	None
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Meighan Girgus	American Heart Association	None	None	None	None	None	None	None
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Tammy Gregory	American Heart Association	None	None	None	None	None	None	None
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Wendy Segrest	American Heart Association	None	None	None	None	None	None	None
Penelope Solis	American Heart Association	None	None	None	None	None	None	None
Clyde W. Yancy	Baylor University Medical Center	None	None	None	None	None	None	None

This table represents the relationships of writing group members that may be perceived as actual or reasonably perceived conflicts of interest as reported on the Disclosure Questionnaire, which all members of the writing group are required to complete and submit. A relationship is considered to be "significant" if (1) the person receives \$10 000 or more during any 12-month period, or 5% or more of the person's gross income; or (2) the person owns 5% or more of the voting stock or share of the entity, or owns \$10 000 or more of the fair market value of the entity. A relationship is considered to be "modest" if it is less than "significant" under the preceding definition.

*Modest. †Significant.

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