Reducing Death and Disability From Stroke
The Role of Governmental Advocacy

Larry B. Goldstein, MD, FAAN, FAHA

Abstract—Governmental actions affect our lives and the lives of our fellow citizens in a variety of ways. This is certainly true for both the conduct of biomedical research and the provision of medical care. Governmental policy-makers require accurate information upon which to base their decisions. Stroke researchers and clinicians are uniquely suited to provide the facts, figures and statistics to help these officials weigh alternative options, and need to become actively involved in the advocacy efforts of their professional organizations. Although written from the perspective of the United States, the issues raised are relevant throughout the world. (Stroke. 2008;39:2898-2901.)

Key Words: stroke ■ public policy ■ advocacy

It would at first seem unusual for an article focused on governmental advocacy to appear in the pages of Stroke, a professional journal providing the results of the latest basic and clinical cerebrovascular disease research. The ultimate objective of developing new stroke-related scientific information is to reduce the human burden of these diseases. Government provides essential tools for achieving this goal. For example, government is the primary funder of stroke research in the United States and in many other countries. After new clinically relevant data become available, the information must be disseminated and incorporated into care. Government, either directly or indirectly, can influence the organization and delivery of health care and can either facilitate or hinder the incorporation of medical innovations into clinical practice. Finally, one of the roles of government is to guard and improve the public health. These activities are accomplished through the activities of a wide variety of agencies based on authority provided by laws and regulations enacted by elected representatives.

Although invoking the political process often carries negative connotations, particularly with respect to the provision of medical care, it provides an essential system for society to resolve conflicts and choose among alternative options. In the best of circumstances, governmental policy-makers should base their decisions on the best available evidence in a way that leads to the greatest overall benefit for the public. By any estimate, stroke is among the most important health issues facing the United States. Stroke remains the third leading cause of death in the country1 with costs estimated to exceed $2.2 trillion from 2005 to 2050.2 Contributors to the journal’s readers, and members of stroke-related professional organizations, have the critical expertise necessary to provide policy-makers with the accurate, scientifically rigorous information they require to inform their decisions.

A variety of professional organizations make important contributions to advocacy efforts aimed at reducing the burden of stroke and cardiovascular diseases. On a national, state, and local basis in the United States, the American Heart Association/American Stroke Association (AHA/ASA) has been involved in stroke-related public advocacy for many years and will be used as an example for this discussion. The Association’s opinions carry considerable weight with legislators and other policy-makers. For example, in 1996, the AHA Office of Public Advocacy helped launch the Congressional Heart Disease and Stroke Coalition, dedicated to providing members of congress with information reflecting the importance of cardiovascular disease and stroke to the American people. An April 2003 national poll conducted on behalf of the AHA found that over three-quarters of adults favored increased federal funding for stroke research, a message that was then incorporated into background information provided to legislators and through congressional testimony by AHA volunteers and staff. These efforts, in part, led to language in the House and Senate 1997 fiscal-year Appropriations Committee reports encouraging the National Institute of Neurological Disorders and Stroke (NINDS) to make stroke research a top priority and to develop an implementation plan. This was then supported by activation of the AHA Stroke Connection, AHA Affiliates, and the AHA Legislative Grassroots Network in a letter-writing campaign asking the President to make heart and stroke research one of the priorities in the National Institutes of Health (NIH) budget. In 2001, the NIH convened a meeting of leading basic and clinical stroke investigators in the first Stroke Progress Review Group (PRG) providing a blueprint for areas of stroke research emphasis (http://www.ninds.nih.gov/find_people/groups/stroke_prg/index.htm). In 2006, a sec-

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Advancing an ambitious stroke research agenda requires adequate funding. The AHA and coalition partners advocated for doubling the overall NIH budget over 5 years to support its research efforts. Congress completed this 5-year effort in 2003, increasing annual NIH funding from $13.6 billion to over $27 billion. Unfortunately, overall NIH funding has been relatively flat since that time (Figure 1). The total budget request for NIH was $28.4 billion in the 2007 fiscal year, the same as was requested for the agency in fiscal year 2006. The NIH allocation for stroke research, approximately 1% of the total budget, has also been flat (Figure 1). NINDS projected that $406 million would be needed in fiscal year 2008 for vital stroke-related research. The available NINDS 2008 fiscal year stroke research budget is estimated to be less than half that amount.

One of the intended byproducts of the doubling of the NIH budget was an increase in the numbers of grant submissions (Figure 2). This was at least in part due to an increase in the numbers of new investigators who were trained during the period of budgetary expansion (less than 20,000 investigators submitted grant applications in 1998 as compared to more than 33,000 in 2007). In addition, the number of submissions per applicant rose from 1.23 in 1998 to 1.38 in 2006. There was a 13% drop in the NIH’s purchasing power in 2008 as compared to 2003 when the doubling was completed because of the lack of subsequent budgetary growth combined with the effects of inflation. The NIH budget for cardiovascular research is estimated to be 15% lower in 2008 than in 2003, after adjustment for medical inflation (calculations by AHA Advocacy staff). As a result, the proportion of submitted grants that are funded has dropped precipitously (Figure 2).

An estimated 21% of first-time grants were funded in 1998 as compared to 8% in 2006 (7% of proposals from established investigators, 9% from new investigators). The overall impact is that trained investigators are being forced to abandon their research programs, highly capable newly trained investigators are not being funded, and prospective investigators are being discouraged from beginning research careers. As reflected in editorials and reviews over the last several years, and written in a joint report by a group of concerned universities and research institutions, “a generation of science is at risk.” Continuing to advocate for appropriate levels of funding for NIH is more important than ever.

Although supporting stroke and cardiovascular disease research is critical, it is also important to translate the fruits of that research into meaningful improvements in public health. At the urging of AHA/ASA and other advocacy groups, and with congressional support, the Centers for Disease Control (CDC) in 1998 began giving states resources under the State Heart Disease and Stroke Prevention Program to improve the prevention and control heart disease, stroke, and other cardiovascular diseases and eliminate race-ethnic, socioeconomic and other disparities. The Association and others supported the elevation of the CDC’s Cardiovascular Branch to its current status as a Division for Heart Disease and Stroke Prevention through report language in 2005. In fiscal year 2007, the CDC was appropriated $44 million for the program with 13 states being fully funded and an additional 20 states and the District of Columbia funded for program-planning. Currently, 17 states receive no funding under the program. Another CDC program, Well-Integrated Screening and Evaluation for Women Across the Nation (WISEWOMAN) screens low-income, under- and uninsured women for stroke and heart disease risk. Since 2000, WISEWOMAN has screened more than 72,000 women, identified over 7300 cases of previously undiagnosed high blood pressure, over 7500 cases of undiagnosed high cholesterol, more than 1000 cases of undiagnosed diabetes, and provided more than 170,000 lifestyle intervention sessions (http://www.cdc.gov/nccdphp/publications/aag/wisewoman.htm). These women receive appropriate education and referral for further care.

Through fiscal year 2007, however, the program was funded in only 13 states and 2 tribal organizations. The Coverdell National Acute Stroke Registry currently funds state-based registries in 6 states to collect data aimed at improving the quality of prehospital and hospital-based care of stroke
patients. The AHA/ASA and partners have consistently advocated for increased funding to support the expansion of each of these programs.

The Centers for Medicare and Medicaid Services (CMS) in the United States is responsible for determining federal reimbursement policy for medical services and thus has a major influence on clinical practice. Services that are covered are more likely to be performed whereas there is a considerable barrier for the provision of those services that are not covered. The advent of intravenous tissue plasminogen activator (tPA) for the treatment of selected patients with acute ischemic stroke was not initially accompanied by appropriate levels of payment for the costs associated with the administration of the drug. Along with others, the AHA/ASA supported the creation of a Diagnosis Related Group (DRG 559) in 2005 so that hospitals would be reimbursed for the costs of treating acute stroke patients with thrombolytic therapy, removing a potential financial impediment to the more widespread use of these drugs. Reimbursement issues related to the use of thrombolytic therapy in the Emergency Department setting in one hospital that subsequently transfers the patient to another hospital for further care are now being addressed. Other important stroke-related reimbursement issues focus on prevention and poststroke rehabilitation. The AHA/ASA and other advocacy groups supported passage of The Medicare Cholesterol Screening Coverage Act that was signed into law as part of the Medicare Prescription Drug and Modernization Act of 2003. The act provides seniors coverage for cholesterol and other cardiovascular screening. Medicare has a cap on reimbursement for outpatient rehabilitation services. The AHA/ASA and partners continue to advocate for the protection of Medicare stroke patients from arbitrary limits on medically necessary rehabilitation services though an exception to these caps. This “exceptions process” was extended by Congress for an additional 6 months in December 2007. Stroke continues to be included on the list of conditions that qualify for an automatic exception for medically necessary therapy services. The AHA/ASA along with others is working to renew the exception for the remainder of 2008 and to make the exception permanent.

With coalition partners, the AHA/ASA has been working to achieve enactment of the Stroke Treatment and Ongoing Prevention (STOP Stroke) act. First introduced several Congresses ago, STOP Stroke would provide funds for a national effort to take advantage of available research to reduce stroke’s burden on the American population by supporting the development of stroke systems of care. STOP Stroke would fund a national information campaign to educate the public about stroke, including prevention, recognition of warning signs and response. It provides a grant program to states to foster the development of coordinated, statewide stroke care systems. A clearinghouse to provide technical assistance to states and share best practices would be established. Finally, there is a provision to support stroke-related training for healthcare providers.

### Table. Examples of Recent and Pending State-Based Stroke-Related Legislation

<table>
<thead>
<tr>
<th>State</th>
<th>Title</th>
<th>Purpose</th>
<th>Status</th>
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</thead>
<tbody>
<tr>
<td>CA</td>
<td>CA A 2721, Tele-medicine Task Force</td>
<td>Intent to create task force to evaluate telemedicine reimbursement</td>
<td>Pending, 2008</td>
</tr>
<tr>
<td>GA</td>
<td>GA SR 30 State Stroke Care System</td>
<td>Creates joint study commission on state stroke systems</td>
<td>Enacted, 2007</td>
</tr>
<tr>
<td>GA</td>
<td>GA S 549 Stroke Centers Three Level</td>
<td>Establishes a three level system of stroke centers, use of stroke triage assessment tool and transport protocols and annual reporting</td>
<td>Reported out of committee, 2008</td>
</tr>
<tr>
<td>IL</td>
<td>H541/S1585 Primary Stroke Center Designation Act</td>
<td>Provides criteria for primary stroke centers and for the Director of Public Health to designate as may hospitals that apply for the designation that meet the criteria</td>
<td>Referred to committee, 2008</td>
</tr>
<tr>
<td>IL</td>
<td>H 5616 Physical Therapy Coverage</td>
<td>Ensures coverage for physical, occupational and speech therapy for stroke victims</td>
<td>Referred to committee, 2008</td>
</tr>
<tr>
<td>MN</td>
<td>H678/S509 Health Bill</td>
<td>Funds for stroke and heart disease prevention programs</td>
<td>In committee, 2007</td>
</tr>
<tr>
<td>MO</td>
<td>S1233 Heart Attack or Stroke Centers</td>
<td>Designates qualified hospitals as heart attack or stroke centers</td>
<td>Introduced, 2008</td>
</tr>
<tr>
<td>NC</td>
<td>NC Stroke Systems Act</td>
<td>Establishes NC Stroke Advisory Council to develop a state stroke system plan, provides funding for the NC Collaborative Stroke Registry</td>
<td>Enacted, 2007</td>
</tr>
<tr>
<td>NE</td>
<td>LR221 Statewide Stroke Registry</td>
<td>Interim study to examine implementation of a statewide stroke registry</td>
<td>Introduced, 2008</td>
</tr>
<tr>
<td>NJ</td>
<td>S967 Primary Stroke Center</td>
<td>Clarifies neuroimaging criteria for primary stroke centers</td>
<td>Enacted, 2008</td>
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<tr>
<td>OK</td>
<td>S1655 Public Health and Safety Stroke Care</td>
<td>Creates and provides requirements for a statewide coordinated system for stroke care</td>
<td>In committee, 2008</td>
</tr>
<tr>
<td>TN</td>
<td>H3903/S4011 Health Care</td>
<td>Enacts Tennessee Stroke Registry</td>
<td>In committee, 2008</td>
</tr>
<tr>
<td>VA</td>
<td>H479/S344 Stroke Triage</td>
<td>Establishes state-wide pre-hospital and interhospital stroke triage plan</td>
<td>Enacted, 2008</td>
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</tbody>
</table>
approved by the Senate Health, Education, Labor and Pensions Committee. It awaits action by the full Senate.

These national efforts complement and support a variety of advocacy activities being conducted in the states with the aide of AHA/ASA Affiliate and state-based staff and volunteers and other groups. Several states have enacted legislation or regulations designating stroke centers with provisions for organizing a system of stroke care. Many engage in public awareness efforts through official recognition of stroke awareness month in May. The Table provides examples of recently enacted and pending state-based stroke-related legislation. Other advocacy activities have been aimed at influencing regulations relevant to the delivery of stroke-related care. In addition to these measures, efforts are being aimed at improving primordial and primary prevention (eg, tobacco control legislation, clean indoor air acts, promotion of physical activity in the school curriculum along with health-related education, etc).

In 1816, Thomas Jefferson wrote to Francis Gilmer, “Every [person] is under the natural duty of contributing to the necessities of the society.” This is no less true today. The readers of Stroke have the knowledge to advance the cause of conquering cerebrovascular diseases beyond their own educational, research and clinical activities. Although this review is presented from a US perspective using AHA/ASA activities as an example, the issues are not unique, and the underlying message is applicable throughout the world. Become involved with your professional organization’s advocacy activities. Your efforts will make a difference. (To find out how to become involved in AHA/ASA advocacy efforts, go to www.yourethecure.org).

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Disclosures

None

References

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