The American Academy of Neurology Professional Association (AANPA) is a worldwide medical specialty society established in 1948 to promote the best possible care for patients with neurological disorders. Comprised of more than 21,000 practicing and research neurologists, the AANPA’s membership includes most of the neurology professionals in the United States complemented by several thousand neurologists from throughout the world.

**President:**
Stephen M. Sergay, MB BCh, FAAN

**St. Paul Headquarters:**
Catherine M. Rydell, CAE
Executive Director/CEO

1080 Montreal Avenue
St. Paul, MN 55116

(800) 879-1960
crydell@aan.com

Rod Larson
Deputy Executive Director

1080 Montreal Avenue
St. Paul, MN 55116

(651) 695-2772
rlarson@aan.com

**Washington Office:**
Michael Amery, Esq.
Legislative Counsel

1501 M Street, NW, 7th Floor
Washington, DC 20005

(202) 747-4847
mamery@aan.com

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EPILEPSY CENTERS OF EXCELLENCE AT THE VETERANS’ ADMINISTRATION

Traumatic brain injury (TBI) is a blow or jolt to the head that disrupts brain function. TBI can compromise the ability to function independently, sometimes for life.

The Problem
TBI is so common among soldiers coming home from Iraq and Afghanistan that many experts are calling TBI the signature wound of the war. Congress has recognized TBI as a major problem and has appropriated millions of dollars for care of our wounded veterans.

The American Academy of Neurology Professional Association (AANPA) urges Congress to continue caring for veterans by targeting VA TBI programs for those veterans who are likely to develop seizure disorders such as epilepsy as a result of TBI.

Specifically, the AANPA asks Congress to support:

Epilepsy Centers of Excellence at the VA Act (S. 2004/H.R. 2818)
The Epilepsy Centers of Excellence at the VA Act has been introduced as S. 2004 by Senator Patty Murray (D-WA) and H.R. 2818 by Congressman Ed Perlmutter (D-CO).

Although data does not exist on post-traumatic epilepsy from the current wars, the statistics from the Vietnam era are alarming. VA-funded research conducted in collaboration with the Department of Defense found that 53 percent of veterans who suffered a penetrating TBI in Vietnam developed epilepsy within 15 years. For these service-connected veterans, the relative risk for developing epilepsy more than 10 to 15 years after their injury was 25 times higher than their age-related civilian cohorts. Experts believe that the rate of epilepsy from non-penetrating TBI will also be high and that the VA is inadequately prepared for a potential epidemic of epilepsy.

The Epilepsy Centers of Excellence at the VA Act will address this glaring need by creating six VA Epilepsy Centers of Excellence across the country. These centers will lead the way in epilepsy diagnosis, research, treatment, and surgery. They will attract the best scientists in the field to conduct state of the art research into different cures and medications for veterans experiencing epileptic seizures. Veterans experiencing seizures will be monitored so they are not lost in the system, and will receive up-to-date care based on their condition. These centers will give our rural veterans the opportunity to get the care they deserve without the cost of always traveling to a VA health care facility.

Epilepsy Centers of Excellence Appropriation
S. 2004 and H.R. 2818 authorize an appropriation of $6 million ($1 million for each center) for each of fiscal years 2009 through 2012 for the support of the clinical care, research, and education activities of the VA Epilepsy Centers of Excellence.

The AANPA supports an appropriation of $6 million for Epilepsy Centers of Excellence in the Veterans Administration Appropriations bill for FY 2009.

What Should Congress Do?
• Cosponsor and support the passage of S.2004/H.R. 2818.
• Support appropriation of $6 million for Epilepsy Centers of Excellence in the Veterans Administration Appropriations bill for FY 2009.

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The mission of the National Institute of Neurological Disease and Stroke (NINDS) at the National Institutes of Health (NIH) is to reduce the burden of neurologic disease through research and by improving treatment and enhancing preventive measures. Since its founding, NINDS has contributed substantially to the modern understanding and treatment of neurologic disorders.

Since Congress doubled funding for NIH, research supported by NINDS has led to the identification of more than 100 genes associated with neurologic diseases. Such gene discoveries have led to therapeutic strategies for ALS, Huntington's disease, ataxias, and muscular dystrophy that are already moving into human clinical testing.

Other accomplishments that are a direct result of NIH research on neurologic conditions include:

- The development of drugs that reduce the severity of symptoms for those suffering with multiple sclerosis and Parkinson's disease
- The identification of more effective stroke treatment and prevention methods
- The creation of new drugs to help prevent epileptic seizures

Unfortunately, recent reduced appropriations to the NIH have severely impaired its ability to sustain these advances. Federal research funding has been inadequate for some disabling neurologic disorders. For example, funding has been especially poor for migraine and other primary headache disorders when considering the prevalence, disability, and economic burden associated with the disease. Migraine afflicts 36 million people in our country. One in twenty-five Americans experiences prolonged headaches 15 or more days per month.

In spite of reduced funding, the NIH continues to streamline and improve research efforts. Examples include Phase I of the John Edward Porter Neuroscience Research Center that houses neuroscientists from eleven NIH institutes and centers that have intramural neuroscience programs. However, for this effort to reach its full potential, funding must be included to complete Phase II.

Few expenditures have paid off more than federal support of the NIH and NINDS. A recent comprehensive review of all phase III clinical trials supported by NINDS—which compare a new agent or intervention (or new use of a standard one) with the current standard therapy—finds that, estimated conservatively, the economic benefit in the US from just eight of these trials exceeded $15 billion over 10 years. The study also found that new discoveries from the trials were responsible for an estimated additional 470,000 healthy years of life. These programs prove their worth every day.

What Should Congress Do?
- Increase NIH funding by 6.6 percent for FY 2009.
- Ensure adequate funding in any appropriations sufficient to complete Phase II of the Porter Neuroscience Research Center.
MEDICARE PHYSICIAN REIMBURSEMENT – THE SUSTAINABLE GROWTH RATE

Background
Physicians are the only providers subject to the Medicare Sustainable Growth Rate (SGR). The SGR cuts payments to physicians if growth in Medicare patients’ use of services exceeds the annual growth in the US Gross Domestic Product.

Medicare payments have not kept pace with physician costs since 2001. Multiple studies have shown that physician acceptance of new Medicare patients is declining. Further cuts in annual updates will result in physicians taking fewer new Medicare patients and fewer physicians participating in Medicare. Both of these effects will have a negative effect on access to care for Medicare beneficiaries.

Congressional intervention has stopped the scheduled cuts for the last two years by freezing physician reimbursement at the 2005 levels in both 2006 and 2007.

Practice Costs v. Annual SGR Updates

What Should Congress Do?
• Pass legislation to avert the 10.6-percent cut in Medicare physician payment scheduled to go into effect June 30, 2008.
• As has been advised by the Medicare Payment Advisory Commission, the AANPA recommends that Medicare physician reimbursement be based on the Medical Economic Index, which measures annual practice cost increases. Paying physicians according to the actual costs associated with treating patients is necessary to maintain consistent access to providers.
• Remove the cost of physician-administered drugs from the SGR as these drugs are clearly not “physician services” as defined by the law.

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A stroke, or brain attack, is caused by the sudden loss of blood flow to the brain or bleeding inside the head, causing brain cells to stop functioning or die. When nerve cells in the brain die, the function of body parts they control is harmed or lost. Depending on the part of the brain affected, people can lose speech, feeling, muscle strength, vision, or memory. Some people recover completely; others are seriously disabled or die.

The American Academy of Neurology Professional Association (AANPA) strongly supports the Stroke Treatment and Ongoing Prevention Act or STOP Stroke Act. This legislation will help ensure that current and future stroke patients receive the most appropriate quality stroke care.

The Problem

- Stroke is the nation’s No. 3 killer and a leading cause of long-term disability.
- Every year, about 700,000 Americans suffer a stroke, and 160,000 of them die.
- On average, every 45 seconds someone in the United States has a stroke and someone dies of a stroke every 3 to 4 minutes.
- African Americans have almost twice the risk of first-ever stroke, compared to Caucasians.
- Today, 5.7 million Americans are stroke survivors, and as many as 30 percent of them are permanently disabled, requiring extensive and costly care.
- Death and disability from stroke are projected to nearly double by 2032.
- It is expected that stroke cost the nation $62.7 billion in 2007. A large share of the direct cost of stroke is met by public payers such as Medicare and Medicaid.

The STOP Stroke Act (H.R. 477/S. 999)

For several years, the STOP Stroke Act has enjoyed broad bipartisan support in the House and Senate. On January 16, 2007, the House legislation (H.R. 477) was re-introduced by Representatives Lois Capps (D-CA) and Chip Pickering (R-MS). The full House of Representatives passed the STOP Stroke Act by voice vote on March 27. Senators Thad Cochran (R-MS) and Edward M. Kennedy (D-MA) re-introduced the STOP Stroke Act (S. 999) in the Senate on March 27, 2007.

The STOP Stroke Act would help ensure that stroke is more widely recognized by the public and treated more effectively by health care providers by authorizing:

- a grant program to help states ensure that patients have access to quality stroke prevention, treatment, and rehabilitation services;
- a national public awareness campaign to educate the public about stroke warning signs and how stroke can be prevented;
- the Coverdell Stroke 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.

What Should Congress Do?

- Support the prompt passage of the STOP Stroke Act (H.R. 477/S. 999).
**UNIVERSAL NEWBORN SCREENING**

Screening newborns for certain congenital, genetic, and metabolic disorders can lead to the early identification and treatment of serious neurological conditions. Early detection can prevent severe disability or death in infants with these rare illnesses.

**The Problem**

Every year newborn screening leads to identification and treatment for an estimated 4,000 infants. Though nearly all children born in the US undergo some screening, the extent and quality of tests vary from state to state. Fewer than half the states routinely test for the full recommended panel of 29 disorders for which effective treatment is available. Depending on the screening done in the state of birth, a child with a given disorder may or may not receive treatment in time to prevent life-long disability or death.

**The Newborn Screening Lives Act of 2007 (S. 1568)**

The Newborn Screening Lives Act of 2007, S. 1568, was passed by unanimous consent in the Senate on December 13, 2007. This legislation would:

- Authorize $15 million for grants to educate health care professionals and families about newborn screening and establish a coordinated support system following diagnosis.
- Authorize $25 million to states to expand and improve their newborn screening programs and encourage states to test for the full panel of disorders recommended by the Advisory Committee on Heritable Disorders in Newborns and Children.
- Reauthorize and expand the role of the Advisory Committee to continuously revise and update the panel of recommended tests.
- Require the Centers for Disease Control and Prevention to ensure the quality of laboratories involved in newborn screening.
- Authorize $15 million to establish a system for collecting and analyzing data from newborn screening programs to help researchers develop a better understanding of the disorders detected by newborn screening and how they might be better detected, prevented, treated, and cured.

**What Should Congress Do?**

- Pass legislation S. 1568 to increase resources for states to expand their newborn screening programs.

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**GENETIC NON-DISCRIMINATION**

**The Problem**

Research gains have led to the availability of increasingly advanced genetic tests that can be used for the medical diagnosis and treatment of individuals. The results of such tests may, however, leave diagnosed individuals vulnerable to discrimination.

**Genetic Information Nondiscrimination Act of 2007 (S. 358/H.R. 493)**

The Genetic Information Nondiscrimination Act of 2007 (S. 358/H.R. 493) would protect individuals from penalization by insurance carriers or employers because of genetic information. The House of Representatives passed H.R. 493 by a vote of 420 to 3 on April 25, 2007.

**What Should Congress Do?**

- Pass legislation (S. 358/H.R. 493) to ensure that genetic information is not used as the basis for discrimination in both health insurance coverage and employment.
FACTS ON NEUROLOGIC DISEASES

There are approximately 600 neurologic disorders—afflictions of the brain and central nervous system. They range from stroke, epilepsy, and Alzheimer’s disease—which affect millions—to rare disorders such as Rett’s syndrome and Rasmussen’s encephalitis. Together, neurologic disorders affect approximately 50 million Americans and cost an estimated $400 billion annually in medical and related expenses.

This fact sheet highlights the impact of several major diseases:

Epilepsy
- Epilepsy and seizures affect more than 2 million Americans—about 1 in 150.
- Epilepsy imposes an annual economic burden of $15.5 billion on the nation in associated health care costs and losses in employment, wages, and productivity.

Headache
- Nearly 28 million Americans have migraine headaches, of which the majority are women.
- Headaches cost the United States approximately $13 billion annually in health care and related expenses.

Alzheimer’s Disease
- About 4 million people in the United States are currently living with Alzheimer’s disease. The number of people with the disease is expected to climb to between 12 million and 14 million by the year 2050.
- Annually, the direct and indirect cost for caring for people with Alzheimer’s disease is estimated to be as high as $100 billion.

Multiple Sclerosis
- Between 250,000 and 350,000 people currently are living with MS.
- MS affects women at almost twice the rate of men.

Traumatic Brain Injury
- Each year in the United States 1.5 million people experience a traumatic brain injury.
- The cost of traumatic brain injury in the United States is estimated to be more than $56 billion annually.

Stroke
- Stroke is the major cause of adult disability and the nation’s third leading cause of death.
- Approximately 700,000 Americans have a stroke each year.
- Total US costs related to stroke are estimated to be between $30 billion and $40 billion annually.

Parkinson’s Disease
- In the United States, at least 500,000 people are believed to have Parkinson’s disease, and about 50,000 new cases are reported annually.
- The total annual direct and indirect cost of Parkinson’s disease is estimated to exceed $6 billion.

Amyotrophic Lateral Sclerosis (ALS)
- About 5,000 people in the United States are diagnosed with ALS each year, and an estimated 20,000 Americans have the disease at any given time.

What is a Neurologist?
A neurologist is a medical doctor with specialized training in diagnosing, treating, and managing disorders of the brain and nervous system. Neurologists do not perform surgery.

A neurologist’s training includes an undergraduate degree, four years of medical school, a one-year internship, and three years of specialized training. Many neurologists also have additional training in one area of neurology such as stroke, epilepsy, or movement disorders. This is called a subspecialty.