

MONTGOMERY COUNTY (MARYLAND) STROKE ASSOCIATION, INC.

Statement
Presented by

Susan H. Emery
President
Gaithersburg, Maryland

on

FISCAL YEAR 2007 APPROPRIATIONS

Before The

APPROPRIATIONS SUBCOMMITTEE ON LABOR-HHS-EDUCATION
U.S. HOUSE OF REPRESENTATIVES

The Honorable Ralph Regula
Chairman

March 29, 2006
2:00 p.m.

Summary of Recommendations

National Institutes of Health: \$29.8 billion

National Institute of Neurological Diseases and Stroke: \$1.6 billion

My name is Susan Emery. I am the President of the Montgomery County Stroke Association and I am a stroke survivor.

Our Association conducts education and supports activities for stroke survivors, their family members, and caregivers. We serve people in the Maryland suburbs of Washington, D.C., and are fortunate to be in the same county as the National Institutes of Health. We have benefited on many occasions by the participation of NIH staff members in our membership meetings. They have been generous in sharing information with us about their research on stroke prevention and treatment.

On December 26, 1965, at the age of nine, I was playing a new game with my brother and a few friends at the kitchen table. That is the last thing that I remember. I was unconscious for the next two days. My mother first learned, incorrectly, that I had spinal meningitis. I was transferred to another hospital where my mother was told that I had little chance of survival. Yet, I am here, more than 40 years later, and I have survived a stroke.

People seldom associate strokes with children. These strokes are rare, but they do happen. There are about three cases of stroke per year in every 100,000 children aged 14 and under. One of the difficulties in dealing with strokes in children is getting the right diagnosis quickly. There are often delays in diagnosis of childhood stroke.

I spent two weeks in the hospital and the subsequent four months in intensive physical therapy. My 10th birthday was spent in the hospital, and I have a picture in my photo album of myself with my mother and a new friend. My right eye is turned down, my mouth is turned down, but I am still smiling. During the four months in therapy at Holy Cross in Detroit, I learned the basics: how to walk, how to talk, and how to move the fingers on my right hand. My mother followed the doctor's instructions and sent me back to school very quickly, where classmates helped me button and unbutton my coat and carry my books, and teachers taped papers to the desk so I could learn to write again. I survived that four months, and would never wish to repeat it.

I have been in therapy six times in my life. I need to tell you about the one time that was the most important to my family. I was 26 years old and had just had my first child. I kept her safe, for I knew my limitations. I always used my left hand to support her. But when she was six months old, she got to be a little heavy, and twice, as I was putting her on the floor to change her diaper, my right hand slipped from under her buttocks. She fell only inches in both cases and did not even notice. But I noticed. I went in for two or three months of therapy close to Denver, Colorado, where I was living at the time. Here, for the first time, they helped my right hand and arm dexterity through occupational therapy. I also learned that I had aphasia—the inability to speak, write or understand spoken or written language because of brain injury—because I called things like fruit baskets “unicorns” instead of cornucopias. Instead of the word being the same, I picked a word that sounded the same. The therapists in Colorado worked with my mind and my body and I will forever be in their debt.

Close to 15 years ago, I made a new life for myself in Maryland. Here, I have been an outpatient at the National Rehabilitation Hospital three times: once for my right foot, once for my Achilles tendon, and once for my right knee. I have seen numerous physiatrists, all of whom are excellent in their field. I have also seen my fair share of therapists. Since I have had therapy on and off for most of my life, I can honestly say that the first few times you go in to see a therapist, you will come out hurting more than when you went in. But in the long run, they help tremendously.

On a work related note, I received a Bachelor of Science in 1978 from Michigan State University in Computer Science and worked for 12 years in the field. I started working in the telecommunications industry in 1990, and got a Master of Science from the University of Maryland, University College in Telecommunications Management. I now work for ITT Industries as a senior engineer on a contract supporting the Federal Aviation Administration's leased telecommunications activities, and have worked with the FAA for more than 10 years. I have done more than survive. I have become a productive member of society.

Stroke research has changed my life. Without the research carried out 40 to 50 years ago, I would not have benefited from electric shock therapy that made me understand the muscles that move my fingers. Without research done 30 years ago, I may not have been able to understand how to exercise my hand for dexterity. Without research performed ten years ago, the people around me would not understand that they need to get me to the hospital quickly if ever I have another stroke. Without current support, researchers may never understand how to stop strokes before they happen or how to make current stroke survivors live healthier lives.

Stroke remains America's No. 3 killer and a major cause of permanent disability. An estimated 5.5 million Americans live with the consequences of stroke and about 1 in 4 is permanently disabled. Yet, stroke research continues to receive a mere 1 percent of the National Institutes of Health budget. I strongly urge you to significantly increase funding for the National Institutes of Health-supported stroke research, particularly for National Institute of Neurological Disorders and Stroke-supported stroke research. NIH stroke research is essential to prevent strokes from happening to children and adults in the first place, and to advance recovery and rehabilitation of those who survive this potentially devastating illness.

Susan H. Emery

Montgomery County (Maryland) Stroke Association President

Susan H. Emery, of Gaithersburg, MD., has a Bachelor of Science degree from Michigan State University and a Master of Science degree from the University of Maryland. She has been working in the private industry for 30 years, and is most recently working with a telecommunications contractor for the FAA.

On December 26, 1965, at the age of nine, Ms. Emery had a stroke. Strokes are rare occurrences for children, and Ms. Emery's mother was told that there was little chance of survival. Even if Ms. Emery did survive, the doctors stated, paralysis and brain dysfunction would occur. Yet Ms. Emery has survived and prospered, and currently assists others who have had strokes.

Ms. Emery is the President of the Montgomery County Stroke Association, Inc. (MCSA), in Montgomery County, Maryland. MCSA provides peer support, counseling, and stroke education to stroke survivors, family members, and the community at large in Montgomery County and throughout the greater Washington, D.C. area. With the dedication of friends, colleagues, and volunteers, the MCSA is able to provide programs for stroke survivors and family members focusing on peer support, counseling, stroke education, referral to local resources, socialization, recreation, and computer-aided speech-language therapy.

Montgomery County Stroke Association was established nearly 25 years ago, and has three Chapters conveniently located throughout Montgomery County, MD. During the 2004-2005 fiscal year, MCSA hosted 70 programs dedicated to caregiver, family member, and stroke survivor support including programs on personal motivation, driver assessment programs, balance and dizziness, exercise, and travel.

MCSA is also involved in community outreach. During May's National Stroke Awareness Month, MCSA dispenses literature including the warning signs of stroke to people exiting grocery stores. MCSA is involved in health fairs, including an upcoming May community health fair at an African Methodist Episcopal Zion Church in Washington, D.C. MCSA has a website (www.mcstroke.org) where families can find basic stroke and disability information, and also produces a monthly newsletter highlighting meetings, contributions, get-well wishes, hospital studies for stroke survivors, and special events.

Stroke research has changed Ms. Emery's life. Without the research carried out 45 years ago, Ms. Emery would not have benefited from electric shock therapy, allowing finger movement. Without research done 30 years ago, Ms. Emery may not have understood how to achieve hand dexterity after stroke. Without research performed ten years ago, hospitals may not understand the correct protocol after stroke. Without current support, researchers may never understand how to stop strokes before they happen or how to make current stroke survivors live healthier lives.

Neither Montgomery County Stroke Association nor Susan H. Emery receives Federal funds or grants.
