



SSEE UPDATE

STROKE SURVIVORS EMPOWERING EACH OTHER

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The First General SSEE Meeting was an incredible success despite the lack of cooperation by the Chicago weather. Coverage of its outcomes will be spread over several issues of *SSEE Update*.

A new column focusing on caregiver topics debuts this issue. It will be featured regularly.

To arrange a SSEE speaker for your group contact Lisa Jones at the AHA/ASA office listed on this page. Feedback and suggestions for the newsletter should be sent to sseeo_il@yahoo.com.

Kathie Kilburg
Editor



"Strike Out Stroke!"

Stroke Survivors Empowering Each Other had their first general meeting on May 11th at Mercy Hospital & Medical Center in Chicago. It was an unqualified success. "Strike Out Stroke" was the theme and Mercy's meeting room, which they generously donated for the day, was almost filled to capacity. Stroke survivors, caregivers and health care providers were all well-represented.

SSEE selected a Chicago location for this year's meeting to provide access via public transportation. A number of participants arrived by Metra from various suburbs. Mercy's van offered pick up service from both Union Station and Ogilvie Transportation Center (the old C&NW). Chicago residents arrived mainly by CTA.

For some that came from as far as Rockford, Peoria and Decatur, it was an overnight trip. We appreciate the effort to join us which was made by all the attendees. Your mere presence spoke volumes about the urgent need for a voice for stroke survivors.

The day kicked off with opening words of welcome from our host, Sister Sheila Lyne, RSM, President and Chief Executive Officer of Mercy Hospital & Medical Center.



Lynette Shaw, MS.Ed., CHES, IL Heart Disease and Stroke Prevention Program, IL Dept. of Public Health next read a proclamation from Governor Blagojevich declaring May "Stroke Awareness Month." The proclamation stated: *stroke is the 3rd leading cause of death in the U.S. striking over 700,000 Americans each year, stroke is a leading cause of long term disability with about 4.5 million stroke survivors alive today, and it annually kills about 7000 to 8000 Illinois residents. About 39,500 stroke patients are discharged annually from Illinois Hospitals costing approximately \$816 million. The proclamation urged awareness of the risk factors for a stroke and the signs and symptoms of a stroke. It advocates for stroke awareness -- an opportunity to educate the public and policymakers about the devastating effects of stroke.*



Master of Ceremony duties were ably shared by founders Mickey Clancy and Lisa Deck. Their personal stories, background on the formation of SSEE and

description of SSEE current structure followed. Participation of attendees was encouraged throughout.



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Dialogue increased considerably during the next sessions -- Making Your Voices Heard, Setting the Agenda, Ranking the Issues,



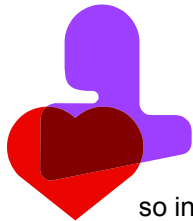
Reporting, Next Steps, and Call to Action. Virtually all tables were heard from. Accounts of difficulties encountered were

remarkably similar, regardless of when or where the stroke occurred. These sessions will be covered in detail in the November 2006 newsletter.



The last part of the day was devoted to Telling Your Story. All of us are called upon to tell our story in some form, whether to respond to a simple "What happened?" query in casual conversation or in a formal media interview. How to derive the maximum impact with your story was described in a presentation by Emily DeSanto, VP Communications, AHA Midwest. It will be the subject of a future issue of *SSEEO Update*.

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The Care Giver

Living Day to Day

As caregivers, we sometimes become so involved in the day-to-day effort to keep things going that we forget that each day is an opportunity to try new approaches or activities that make a positive difference in our life and our stroke survivor's life. Some things to bring about positive changes for the better:

- ✚ Stand back and take a look at your situation -- what works well and what doesn't -- and find ways to make changes for the better
- ✚ Establish **routines** that effectively meet your care receiver's needs
- ✚ Find ways to economize on your work load
- ✚ Employ home or health care personnel who demonstrate that they really care and who work to foster independence
- ✚ Improve your physical surroundings
- ✚ Physical, speech and occupational therapy; exercise
- ✚ Assistive devices, which range from special eating utensils to specially equipped phones, that increase independence and safety
- ✚ Improve nutrition

- ✚ Carefully monitor medications and their interactions
- ✚ Intellectual stimulation
- ✚ Social interaction
- ✚ Spiritual renewal
- ✚ Fill each day with activities that you can both look forward to

Hands-On Caregiving

If your stroke survivor needs considerable help, a well-planned routine can make the more demanding parts of your caregiving day go more smoothly, take less time and help prevent avoidable problems.

- Put needed information into a clearly marked notebook and keep it where easily found. It can be used by anyone filling in for you to know exactly what is needed and what to do. Include lists of:
 - Emergency contacts in addition to 911
 - Medical personnel with their area of expertise, addresses and phone numbers
 - Home health agencies
 - Other people who can help or fill in when needed
 - Lawyers and financial advisors
 - Medications, when they are to be taken, and where they are stored
 - Where needed items are kept, such as thermometers and blood pressure monitors
 - Morning and bed time routines
 - Exercise and therapy schedules and directions
 - Make a list of all the things you need for morning and bedtime routines, buy several of these items, and have them close at hand, such as bathing items, medications, and clothing. This time-saver keeps you from having to search or leave the room for them when you are helping your stroke survivor. If you use items in several different places, have duplicate items stored in these rooms, e.g., the bath and bedroom.
 - If possible, have someone help you with the morning and bedtime routines. They are often the most challenging times of the day.
 - Those with cognitive impairments may need reminders about or assistance with personal hygiene. Practice good oral hygiene -- tooth brushing, denture cleaning, and gum cleaning -- preferably after every meal. It prevents gum disease, tooth decay and loss, as well as secondary infections that result from poor dental care.
- If your care receiver is incontinent, it is important to ensure cleanliness. Use protective (barrier) creams and change incontinence aids and clothing as needed. Poor hygiene can result in diaper rash,

blistering of the skin, and decubitus ulcers (pressure sores) that cause discomfort and serious infections.

- Persons with limited movement should be turned in bed on a regular basis to prevent pressure sores. Correct bedding, such as sheepskin, egg carton bed coverings or an air mattress, prevents pressure sores. Move them at least once an hour to reposition them, do range of motion exercises, or have them sit in chairs that offer sufficient support.

Do whatever you can to keep to the same routine if there has been cognitive or memory impairment. Memory loss is common with stroke survivors. Repetition may aid recollection. Preserve habits, stay with the familiar, maintain schedules to act as prompts or reminders. Buy the same brands for familiar packaging or place the product in the same location on the counter to help the stroke survivor's recognition.

Tips on Safety

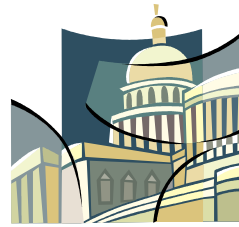
Be sure that the stroke survivor:

- Uses a cane or walker, if needed.
- Has a clear path through each room, including the bathroom and kitchen. Remove rugs that can be tripped over, including throw rugs. Stop waxing slippery floors. Evaluate all-weather carpeting in the bathroom to help prevent falls.
- Is secure in their wheel chair. A tray that attaches to the wheel chair can prevent falls and provides a place for drinks, books, etc. Be sure that the wheels are securely locked when doing transfers.
- Cannot fall out of bed. You can place a chair or other guards next to the bed, and position your stroke survivor in the middle of the bed so that they can turn over without fear of falling.

Make sure there are working smoke detectors on each floor of your house. Quick, easy, and readily available ways to communicate with others in an emergency are critical. Consider these options:

- An intercom to summon assistance from another room.
- A cordless speaker phone with memory. It fits in a pocket and you simply hit one button to reach help.
- A specially equipped phone with speed dial, a large digital display for easy reading, and ring and voice enhancer for those with vision/hearing problems.
- A signal system to summon outside help with the push of a button.
- A cellular phone. Important if you travel.
- Ask your local Area Agency on Aging (county, township, local police or post office) about visitor and phone reassurance or monitoring programs.

Source of excerpts: Dept of Health and Human Services, Natl Family Caregiver Support Resource Room, "Because We Care", website



What's New in Washington, D.C.?

A Federal Update from Lisa Deck

You're the Cure Advocates Urge Congress to Make the Nation's No. 1 Killer a National Priority

The fight against heart disease and stroke took center stage on Capitol Hill on May 16, 2006 during the American Heart Association's annual Lobby Day. Nearly 550 *You're the Cure* advocates, including heart disease and stroke survivors, caregivers, researchers and healthcare professionals, came to our nation's capitol to deliver a lifesaving message to members of Congress – "You are the Cure for Heart Disease and Stroke." This year's delegation, which included *You're the Cure* advocates from all 50 states and Puerto Rico, participated in 394 scheduled meetings with lawmakers and many informal "drop by" visits.

Illinois had 29 delegates and five SSEEO members attending this event. The advocates urged members of Congress to:

- Significantly increase funding for heart disease and stroke research funded by the National Institutes of Health;
- Significantly increase funding for the Centers for Disease Control and Prevention's Heart Disease and Stroke Prevention Program, which provides states with grants to implement tailored programs to help prevent and control heart disease, stroke, and other cardiovascular diseases;
- Support the HEART for Women Act – legislation aimed at improving the prevention, diagnosis, and treatment of cardiovascular disease in women.

Members of Congress have responded in record numbers to the personal stories *You're the Cure* advocates shared in their legislative meetings and the follow-up they conducted when they returned home. As of May 30th, 117 Representatives and 30 Senators have signed the Dear Colleague letter calling for increased funding for prevention and treatment of heart disease and stroke. We have also seen growing support for the HEART for Women Act, with an additional 50 members of Congress joining as co-sponsors since Lobby Day.

Other Lobby Day activities included the Survivors Luncheon, the Volunteer Awards ceremony featuring a special tribute to the late Lynn Smaha, M.D., former president of the AHA, the kick-off breakfast with special guest speaker Senator Lisa Murkowski (R-AK), and the reception to celebrate the new CDC Heart Disease and

Stroke Prevention Division. "As a stroke survivor, I enjoy planning and facilitating the Survivor's Luncheon which allows us to share our thoughts and ideas with each other" said Lisa Deck.

Three of SSEEEO's founders, Mickey Clancy, Yvonne Stovall and Lisa Deck, as well as two Steering Committee members, Ted Lisowski and Mary Kay Ballasiotes, participated in the two-day event in Washington, DC. They were able to speak with congressional representatives from Chicago, Lombard, Bolingbrook and Flossmoor. Mickey Clancy commented, "The speaker at the Survivor Luncheon made me believe my voice as a survivor can and will make a difference."



Your support and commitment to the fight against heart disease and stroke is what made Lobby Day such a success. **To learn if your legislator has supported our Lobby Day asks, please follow the links below:**

Dear Colleague House:

<http://www.heart.org/presenter.jhtml?identifier=3039709>

Dear Colleague Senate:

<http://www.heart.org/presenter.jhtml?identifier=3039750>

HEART for Women Act House:

<http://www.heart.org/presenter.jhtml?identifier=3039745>

HEART for Women Act Senate:

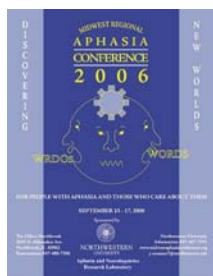
<http://www.heart.org/presenter.jhtml?identifier=3039747>

Changes in Medicare for Stroke Patients

On February 15th, stroke patients needing extensive outpatient rehabilitation became eligible for an automatic exception to the \$1,740 limit on therapy services that took effect January 2006.

Source: Portions of this column were taken from the AHA's June 2006 Advocacy Pulse and Spring 2006 Heart and Stroke News.

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"Discovering New Worlds" Midwest Regional Aphasia Conference

September 15 -17, 2006
Hilton Northbrook
2855 N Milwaukee Av
Northbrook, IL

Aphasia is a disorder of the brain that affects one's ability to communicate, disabling a person's ability to speak, read, write, or understand the spoken word. People with aphasia have healthy minds, but they are often unable to express even the simplest thoughts, needs, or desires. Aphasia is truly a "silent" disability.

Aphasia can be so severe that it can make communication almost impossible. Can you imagine being locked inside your body, understanding all that goes on around you and not being able to express yourself? Even though aphasia does not affect a person's intellect, people with aphasia are often assumed to be mentally challenged, deaf or even intoxicated. Many people with aphasia are unable to work because of speaking and writing impairment. Many more live in isolation. This is one of the most frustrating and devastating of disabilities, caused by a stroke or other brain injury.

Learn about the challenges of living with aphasia and the newest developments in aphasia therapy. Attend workshops on recreational sports, vocational training, humor, and life after aphasia, both for caregivers and aphasia survivors. Listen to an expert panel sharing their work and answering questions. For more information about the conference, **contact Michael Dickey at m-dickey@northwestern.edu or at (847) 491-2417.** Details about the conference schedule and lodging are at <http://www.midwestaphasiaconference.org>

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A Camping Experience for Stroke Survivors & Their Caregivers

Stroke Retreat

Living Springs Camp
Lewistown, IL 61542

September 22, 23, & 24, 2006

or

October 27, 28, & 29, 2006

A getaway weekend for stroke survivors, caregivers and family members of all ages. Living Springs is a camp located in rural Fulton County about 45 miles from Peoria.

Staff will be on hand to assist with the caregiving needs of the stroke survivor. Activities are planned for both the stroke survivor and caregiver so all participants can spend some private time getting back to nature. Lodging is in 2 – 4 person cabins with nearby bathhouse or rooms in the lodge with private baths. Living Springs has some handicap accessible rooms available.

The retreat cost is \$75.00 per person (a limited number of scholarships are available). This includes: 2 nights lodging and meals from Friday afternoon to Sunday lunch. Please note that at least one caregiver must attend with each stroke survivor. Registration forms and further information is available by contacting Marylee Nunley at maryleen@insightbb.com or by phone at 309-681-5652 (days) or 309-693-2375 (evenings).

Visit their Website at <http://www.strokecamp.com>.

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