



SSEE UPDATE

STROKE SURVIVORS EMPOWERING EACH OTHER

Volume 2 Issue 1 February 2006

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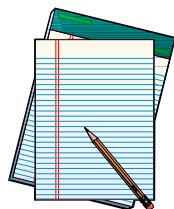
Welcome to 2006. The end of the year was busy – holidays, learning about printing schedules, mastering use of the postage meter machine. The first issue of this newsletter took a tad longer to produce than we anticipated. But as we gain experience, we will get better and faster at it.



To close out 2005, Yvonne Stovall (one of SSEE's founders) was a featured speaker at a Conquer Smoke and Stroke luncheon in DuPage County. She did a great job inspiring her audience with her story of surviving stroke. To begin 2006, Mickey Clancy (another founder) will talk to the SSCORE Stroke Group at Marianjoy Rehab Hospital in Wheaton. Both of them will be at Van Matre Hospital in Rockford (Feb.28) and Mercy Miracles at Mercy Hospital in Chicago (Mar. 9).

To arrange a SSEE speaker for your group or if you have general questions regarding no-cost membership, contact Lisa Jones at the AHA/ASA office listed below. Feedback to this newsletter is welcomed. Any suggestions – newsletter name, articles, regular features – can be sent to sseeo_il@yahoo.com. Feel free to copy and distribute SSEE Update. Copyright articles are noted as such. Enjoy!

Kathie Kilburg
SSEE Steering Committee



Notes from Lisa

Happy New Year! As 2006 begins, we at SSEE are excited about the beginning of our organization. My name is Lisa Deck, and I am one of the founding members of SSEE. As Mickey Clancy, a fellow founding member, discussed in our first newsletter, we're here to gather and unify a group of stroke stakeholders to make a difference in our lives and the lives of all affected by

stroke, and ultimately make a change in health policy towards stroke.

The effects of stroke have been thrust to the forefront of current events lately. Dick Clark and Ariel Sharon have both suffered strokes. While the ramifications of Sharon's stroke have yet to be realized, Dick Clark appeared on television on New Year's Eve for the first time since suffering a stroke in December 2004. In the USA Today, reporter Liz Szabo states "Clark's appearance exposes unease with stroke patients." Television icon's courage is praised. Dick Clark has shown the world how stroke patients are affected, what a battle fighting back can be, and how overcoming a stroke doesn't necessarily mean life goes back to the way it was. Yet, life goes on and we at SSEE credit Dick Clark for his bravery and spirit!

As these worldwide figures have shown us, stroke affects everyone. I learned this at an early age of 21 years old, when out of the blue, I, a healthy, athletic, ready-to-face-the-world young lady, suddenly found myself unable to move my left side, confused and suffering from a severe headache. This was my first of three strokes and the beginning of my journey to battle a life-threatening illness. Becoming involved with SSEE has been a wonderful blessing for me. Although I just turned thirty, this group is a combination of many types of people, all who have battled stroke, and want to make a difference, for themselves, their relatives, fellow survivors, and the general public. Nowhere does a group like this exist -- until now.

I live in Washington DC, so you may wonder how I became a founding member of SSEE, a group based in Illinois. Again, it all started with my first stroke. When I started to recover from my three strokes and brain disease, I decided to get involved with my local Train to End Stroke marathon program. I held a Dinner Dance and Silent Auction and rose close to \$12,000 for the American Stroke Association (ASA). This began my involvement as a stroke volunteer for ASA. In Washington, DC, I was fortunate to get involved with ASA's National Advocacy office. Here, I was able to work with national volunteers and advocates, meeting a huge variety of survivors of heart disease and stroke. One of those people I met was an Illinois-based staff member, Mark Peysakhovich, who told me about his desire to bring together stroke survivors in an effort to make a difference

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in public policy. I wanted to do the same thing, so we joined forces.

I cherish the opportunity to work with this wonderful group of survivors from Illinois. I think you will too. The dedication and enthusiasm of these SSEEO volunteers is unparalleled. The organization and daily work of these folks continue to impress me. I am honored to be working with this heterogeneous group, who, despite our external differences, work together for the same purpose -- to give a voice to the group of stroke survivors and their stakeholders to stimulate real policy change in Illinois.

We hope this is the beginning of an organization that can eventually be modeled or copied throughout the nation. SSEEO has this possibility. Don't you want to be a part of this movement?? Together, we can make a collective, significant difference in the lives of all living with stroke.

Stroke Survivors Empowering Each Other. I know you'll find this power with our group. We hope you join us soon! Contact Lisa Jones at lisa.jones@heart.org to receive information about SSEEO, or to discuss the possibility of a SSEEO member to come speak to your support group. We'd love to work with you!

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Stroke is a leading cause of adult disability and the third leading cause of death among men and women in the states of Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin, accounting for over 25,000 deaths or 5.7 percent of all deaths that occurred in the total population in the Great Lakes region in 2002. According to estimates from the Behavioral Risk Factor Surveillance System survey and other state administered surveys, more than 880,000 persons are living with the aftermath of a stroke in the Great Lakes region.

Stroke is primarily a disease of lifestyle, and is largely preventable through risk factor awareness and modification. Risk factors for stroke that can be modified or treated include: high blood pressure, heart disease, atrial fibrillation, smoking, diabetes, obesity, and elevated blood cholesterol. Three of the six Great Lakes states have a higher percentage of adults who have high blood pressure, a poor diet, and are physically inactive than the U.S. median. Four of the six states have a higher percentage of adults who have diabetes, high cholesterol, and smoke than the U.S. median. Five of the six states have a higher percentage of adults who are obese than the U.S. median.

The mission of the Great Lakes Regional Stroke Network (the Network) is to optimize collaboration and coordination among the Great Lakes regional states to reduce the burden of stroke and disparities. The Network works through a state advisory board, steering committee, work groups, and individual state stroke task forces/committees to share experiences and resources across six states to implement a common public

health plan for stroke. The Network includes state health department, heart disease and stroke prevention staff and state stroke task force/committee members in Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin.

The Illinois Department of Public Health receives funds from the Centers for Disease Control and Prevention (CDC) to serve as the administrative and fiscal agent for the Network. The Illinois Department of Public Health contracts with the University of Illinois at Chicago (UIC) Department of Neurology and Rehabilitation's Center for Stroke Research to provide scientific and administrative support for the Network's activities.

Excerpts reprinted with the generous permission of the Great Lakes Regional Stroke Network, The Burden of Stroke in the Great Lakes States, January 2006. For more information, go to <http://glrsn.uic.edu>.

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Illinois Stroke Task Force

Stroke Systems of Care in Illinois – In 2002, there were 30,713 deaths in Illinois due to heart disease and 7,171 deaths due to stroke.

The Illinois Stroke Task Force, which is a 24-member appointed task force, hosted its first meeting on June 9th, 2005. The task force membership includes two stroke survivors in addition to a number of diverse health professionals. The Recommendations for the Establishment of Stroke Systems of Care were shared at the first meeting. These recommendations were published by the American Stroke Association in February 2005, and notes that building stroke systems throughout the United States is the critical next step in working to improve patient outcomes in the prevention, treatment and rehabilitation of stroke. The current fragmented approach to stroke care in most regions of the United States provides inadequate linkages and coordination among the fundamental components of stroke care.

The core areas for setting priorities include:

- Primary Prevention/Public Education
- EMS Notification and Response
- Acute Care
- Sub-Acute Care and Secondary Prevention
- Rehabilitation

The Illinois Department of Public Health through the Illinois Stroke Task Force has developed draft priorities focused on the core areas above and will be finalized in the near future. For additional information, please contact Heather Gavras at 630-789-9222 or at heather.gavras@heart.org.

Heather Gavras, MPH, RD
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Stroke Connection Magazine is available FREE to stroke survivors. This publication by the American Stroke Association offers great information for those recovering from a stroke. It includes practical tips for daily living and news on stroke research, along with inspirational stories from survivors.

Please subscribe FREE by calling 1-888-478-7653 or online at www.strokeassociation.org/strokeconnection



Start Small

The holidays are often a time of overindulgence followed by regrets over those second helpings of our favorite foods, snug-fitting clothes and broken New Year resolutions. Rarely does our

weight ever stay the same – it is either going up or down. To change the direction that scale is taking...

Exercise More

The idea is to use up more calories than you eat. You need to use up the day's calories and some of the calories stored in your body fat to lose weight.

Work towards exercising at least 30 minutes most days of the week. Try brisk walking, if you are able. If not, do whatever exercise you can, but do it consistently. Walking is difficult for me, so I joined the fitness center at my local park district. I hesitated at first, picturing the active, slim models of the television commercial for a local health club.

The Americans with Disabilities Act (ADA) prohibits discrimination against, or segregation of, people with disabilities in all activities, programs, or services—including fitness facilities. Health or fitness programs provided by local governments, such as parks and recreation programs, must be accessible since they receive public funding. Privately-owned health clubs are considered “public accommodations” and are expected to remove barriers when it is “readily achievable” to do so.

The park district health club in my community of 35,000 has a varied membership. Young healthy women doing aerobics mix with young guys pumping iron. But interspersed in the mix are seniors, a few people undergoing cancer treatment, a couple of wheelchair users, several cardiac rehabbers, and me. Although in the minority, the disabled are welcomed – not stared at. Most park districts with fitness centers have a senior membership rate, and some will even extend that reduced rate to those under 65 who are disabled.

The recumbent bicycle was used in the physical therapy program I was in years ago. So it was familiar sight when I entered my health club. Its chair-like position with back support and your legs extended in front, rather than straight down, is often more comfortable than a typical cycle. The effort is adjustable, so you can start off easy and add more difficulty and time as you build up. It is a good alternative to walking. Others to try are aquatic exercise or yoga. Remember, start small and gradually build up.

Eat Less and Better

Fresh is best. Read food labels to choose healthy foods for losing weight.

- Eat plenty of fresh vegetables, fruits, and whole grain products.
- Eat less sugar and fewer sweets. Look for hidden sugar on labels, such as corn syrup, sucrose, glucose, lactose.
- Choose foods whose labels say low, light or reduced to describe fat or calories. Reduce saturated fats and trans fatty acids.

- Choose skim milk products and reduced fat cheeses; fat-free or low-fat sour cream and yogurt.
- Use fat-free frozen yogurt to replace ice cream.
- Select lean cuts of fish, poultry and meat. Trim skin and fat. Reduce portion size.
- Broil, roast or steam foods.
- Use fresh lemon, herbs or spices to season food, rather than rely on table salt. Watch the sodium content of foods such as cereals and soups.

Put a few of these tips in play TODAY. Start with small changes and get used to them. Then add more when you can.

Eat a Wide Variety of Foods

Variety in the diet helps you get all the vitamins and other nutrients you need and prevents boredom, which can lead to overeating. Treat yourself, sometimes. But eat only a **small** amount. And make it an **occasional** treat. Be sure your other foods that day are low in fat and calories.

If you are going out for dinner, try asking for a ‘to go’ container for leftovers at the beginning of your meal rather than the end. Cut your meal in half and pack the remainder away for another day. Now enjoy the smaller portion.

Keep fresh fruit in the house if sweets are your downfall. Cut-up and wash fruit as soon as you bring it home from the store. Make it as easy to grab an apple, orange, banana, grapes or cut-up pieces of melon as it would be to reach for that donut or handful of cookies.

Banish store-bought packaged cookies from your house. If I just must have that chocolate chip cookie (my weakness), I make myself work for it. A package of refrigerated, break-apart cookie dough is always kept in my fridge. Chocolate chip cookies are a lot less enticing when you know you have to bake them first. Avoid highly processed convenience foods.

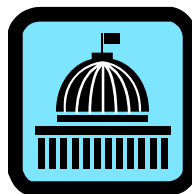
Ask Your Doctor

There are some stroke risk factors that you cannot control -- age, sex, race/ethnicity, family history, and prior stroke. Focus on those you can control! Risk factors for stroke that can be modified or treated include: high blood pressure, heart disease, smoking, diabetes, obesity, and elevated blood cholesterol.

Better nutrition and an increase in physical activity may not only result in weight loss, but have a beneficial effect on blood pressure, cholesterol, and general health. Questions about weight loss or exercise? Ask your doctor.

Sources: U.S. FDA, Losing Weight Safely, June 1998
North Carolina Office on Disability & Health/The Center for Universal Design, Removing Barriers to Health Clubs and Fitness Facilities, 2001
The Burden of Stroke in the Great Lakes States, January 2006.

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Springfield Update

2006 State Policy Priorities of the American Heart Association and the American Stroke Association

REVERSING THE EPIDEMIC OF CHILDHOOD OBESITY

More children in Illinois are more obese than ever before – and many of them are developing life-threatening chronic illnesses much earlier in life than their parents. Although it is impossible to legislate healthy behavior, the Illinois General Assembly can do a great deal to help Illinois kids become healthy adults:

- **Close the physical education waiver “loophole” for school districts in Illinois.** Currently, any school can receive a waiver from state physical education requirements for almost any reason. And even as PE programs are improving and focusing on nutrition and physical activity, over one-third of the school districts in Illinois have been allowed to cut or eliminate PE with little or no feedback from parents or the local community.
- **Help students eat healthier by improving their food choices in schools as well as their nutrition education.** Give students healthier alternatives in the school cafeteria and in school vending machines. Encourage local schools to procure produce from local farmers. Require profits from school vending machines to be used to promote physical activity and nutrition.

STRENGTHEN THE CHAIN OF SURVIVAL

There are four links in the Chain of Survival for cardiac arrest: 1) Early Access to Care; 2) Early Cardiopulmonary Resuscitation (CPR); 3) Early Defibrillation (AEDs); 4) Early Advanced Care. Stroke care providers must develop systems of care to improve each link in the chain of survival in preventing and treating stroke. The Illinois General Assembly should:

- **Encourage teachers and students to learn CPR and AED use.** Teachers learning these lifesaving skills should be able to count the training towards their professional development and continuing education requirements. Students should be encouraged to take such training as part of any existing or new community service requirements.
- **Improve the state stroke system.** Over the last decade, scientists and doctors have made dramatic breakthroughs in the prevention of, response to and treatment of stroke. However, emergency responder education, investment in medical infrastructure and other improvements in stroke systems have not kept pace.
- **Provide funds to assist local communities and units of government in purchasing automated external defibrillators and in training appropriate personnel in CPR and AEDs.** Chances of survival from cardiac arrest increase by over 60 percent if an AED is immediately available to revive the victim.

PROTECT CITIZENS FROM TOBACCO

- **Utilize payments established under the national Master Settlement Agreement between tobacco companies and the states to fund tobacco prevention for young people and tobacco cessation services for smokers.** Scientific evidence proves that prevention and cessation programs work. Over the last several years the demand for services in Illinois has significantly increased while tobacco funds have been cut.

- **End the practice of selling cigarettes and other tobacco products to underage minors.** The current system does little to discourage retailers from selling tobacco to minors. The State of Illinois should enact provisions that will license and regulate the sale of tobacco in a manner similar to the system in place for alcohol sales.

For further information, please contact Mark Peysakhovich, Senior Director of Advocacy for the American Heart Association and the American Stroke Association at 800-677-5481, ext. 6644 or at mep@heart.org.

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Support Group Corner

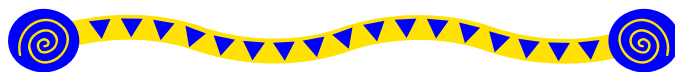
‘Ask Your Pharmacist’ is one of the popular annual presentations at SSCORE, the stroke support group held at Marianjoy Rehab Hospital in Wheaton.

The pharmacist from a local big-box store talks about the standard categories of medications (e.g., blood pressure, blood thinners, statins) typically prescribed to stroke survivors. The classes of drugs within each category are described (e.g., ACE inhibitors, beta-blockers for hypertension). The differences between them, benefits and side-effects are covered. Besides adverse interactions between prescription medications, interactions with over-the-counter drugs and certain foods are identified.

Attendees can submit their questions in writing to maintain privacy. Alternatives to a medication causing side-effects are often suggested. The pharmacist talks about medications, including generics, newly available. Learning more about the medications taken often leads to further discussion during the next doctor’s visit.

Please share your experiences and Support Group program ideas. Send your suggestions for this column and updated Support Group contact/ mailing info for a future publication of Stroke Support Groups in Illinois to sseeo_il@yahoo.com.

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SAVE THE DATE!!

“STRIKE OUT STROKE”-1st Annual SSEEО General Meeting

We are planning the first SSEEО general meeting so I want you all to save the date of **Thursday, May 11, 2006**. The tentative location is Mercy Medical Center in Chicago for the daylong seminar. We will have activities as well as informational sessions. So, please save the date and as the plans move ahead, we will keep you informed.

Thank you,
Mickey Clancy

