



SSEE UPDATE

STROKE SURVIVORS EMPOWERING EACH OTHER

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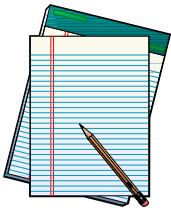


Welcome to the inaugural issue of SSEE Update. Although, as an organization, we're still in the formative stages, we want to keep you informed of our progress. You can expect at least 4 issues of this newsletter a year plus periodic Legislative Alerts. We will try to include items that are relevant to stroke survivors, their family and friends and their support groups.



Feel free to copy and distribute this newsletter. Copyright articles are noted as such. We will work on having an e-mail version available in 2006. Feedback to this newsletter is appreciated. Any suggestions - newsletter name, articles, regular features - can be sent to sseeo_il@yahoo.com. General questions regarding SSEE membership or speakers should be directed through the AHA office listed below. Enjoy!

Kathie Kilburg
SSEE Steering Committee



Notes from Mickey

Expansion Drive

I'm Mickey Clancy, one of founders of Stroke Survivors Empowering Each Other (SSEE). SSEE was started by 5 stroke survivors in September 2004. Four of us live in the Chicago area - Yvonne Stovall, Jean Sullivan, Nira West, and me. The fifth, Lisa Deck, resides in Washington DC and is a volunteer in the AHA Federal Advocacy office. We started SSEE because stroke survivors as a group do not have a lobby voice with local state or federal legislators. It seems every other group has a specific lobby -- physicians, teachers, automakers, even heart disease survivors have a lobby (the Mended Hearts program). We formed SSEE to have a similar voice.

We also want to build SSEE into an umbrella organization for all stroke survivors, their families and friends and their support groups. Our initial focus is Advocacy, but we hope to grow to be a resource for questions and needs of stroke survivors (e.g., a Peer Visitor program). The mission statement for SSEE is: To provide a common voice for stroke survivors and the people in their lives.

We all became members of this community by surviving a stroke or being affected by it in some way. SSEE is a means to draw this community together and make it more effective and more "visible" (see Lin Wisman article from The Stroke Network that follows). There is no cost to join SSEE.

Right now we have a Steering Committee of 10 -- some survivors, some caregivers. We want to expand our Steering Committee and membership throughout Illinois. Stroke affects people of all ages, gender, geography, race, religion, ethnicity -- we expect to reflect that.

With the assistance of the American Stroke Association, we have developed a SSEE brochure which includes a sign up sheet. A web page and 1-800 number are currently being discussed. We are also in the process of forming a Medical Advisory Board.

Throughout 2005, Yvonne and I have been able to meet a number of you through your Stroke Support Groups. Some of those groups have been large and well-established. Some have been small and just starting up. We plan to do more of that in 2006. If you would like me or one of the other Founders to speak at your Support Group meeting call Lisa Jones at the AHA office to set it up. Many issues are raised at these sessions which we plan to address -- access to family restrooms, help with the cost of OTC medications that have been prescribed, availability of additional therapies when needed, rental cars for drivers with right side paresis.

With this first issue of SSEE Update, I wanted to keep you informed about where we are in the membership gathering stage. We have not forgotten about any of you and don't want

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you to think we have. We are currently at a membership in the hundreds and growing. That is very exciting! And as the new year approaches, hopefully those numbers will increase.

Thank you all for your patience while SSEEEO grows. Remember we are all in this together!

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The Invisible Stroke Survivor

By Lin Wisman

For some time now I have been troubled by not seeing stroke survivors. There are estimated to be 2 to 4 million survivors (depending on whose doing the counting) in the US alone. Where are all these people? They are not in sight.

When I go about my daily tasks I very rarely see anyone who displays any stroke residuals. I know there are many people who have had strokes who don't show any outward signs. But, there are many who do. Where in the world are they?

I regularly visit the grocery store, post office, other stores, and medical offices. It is rare to see any type of disability. Where are they hiding? Most of the people who occupy all the handicapped parking places must be those who are not visibly disabled. I rarely see the visibly disabled.

Four thousand people have registered with The Stroke Network. And that includes survivors, caregivers, family and other interested people. Why aren't more people using the site for support and information? I know there are more than have used the site, but not registered. But, even if that brought the number to 20,000 what has happened to everyone else? Not everyone uses the internet for information. Some do not have internet access. Some have never taken up the habit of using the internet. Still, why aren't more people in evidence?

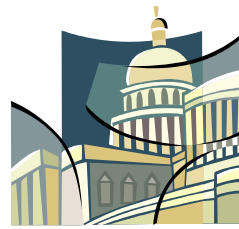
The world is not very welcoming to those who are disabled. It is difficult to participate in many activities if one is not able bodied. But that does not fully explain why there are so few stroke survivors in public. One problem is that this promotes the belief that those with disabilities -- stroke survivors as well as others -- are few. It also promotes the belief that stroke survivors are all older (30% are under 65). It promotes the belief that there is no life after stroke.

I for one would like to change perceptions. More stroke survivors need to be out and about. More stroke survivors need to be examples to all they meet. One reason is that if the disabled were more visible others might see their future or the future of someone to whom they are close. One would like to think it would give some people pause to think about their and their loved ones health.

I now begin each week asking my self how to make stroke survivors more visible. I also think about how I personally can be part of stroke education. One way I do that is by talking with strangers. I have a series of stroke education comments. I suppose some people think I am crazy. But, I like to think I am doing a bit to help.

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What's New in Washington?

A Federal Update from Lisa Deck

SSEEEO: As a group of stroke survivors and supporting parties, we must not only care about legislation in the state of Illinois, but also the policies of the Federal government. Currently, the Stroke Treatment and Ongoing Prevention Act (STOP Stroke Act) is active in the legislative process on Capitol Hill. The passing of the STOP Stroke Act would greatly support the goals and ideals of SSEEEO. Here is a bit of information for us to consider as we move forward as an organization.

Position:

The American Heart Association and its American Stroke Association division strongly supports the Stroke Treatment and Ongoing Prevention Act (STOP Stroke Act) to help ensure that stroke is more widely recognized by the public and treated more effectively by healthcare providers. The Association urges Congress to pass this important legislation this year.

Background:

On June 14, 2004, the House version of the legislation was passed by unanimous consent. The Senate bill was referred to the Committee on Health, Education, Labor, and Pensions (HELP). As the 108th Congress drew to a close, Senators Cochran and Kennedy worked to draft language for the FY 2004 Labor-HHS Appropriation bill. Unfortunately, the Senate was unable to secure additional funds and the language was dropped.

On February 17, 2005, the House co-sponsors reintroduced their version of the legislation, H.R. 898, and the Senate cosponsors followed suit in May, introducing S. 1064. The House bill may move through the Energy and Commerce Committee and chamber floor soon, and it is hopeful that the Senate HELP Committee, which is under new leadership, will move forward too.

Facts:

The STOP Stroke Act proposes to:

- **Raise public awareness** – by authorizing funding for a national public information campaign to educate the public about stroke, including how to prevent it, how to recognize the warning signs and the importance of seeking immediate treatment;
- **Help states fight stroke** – by establishing a grant program for the design and implementation of statewide stroke care systems and support networks;
- **Collect and disseminate data and best practices information** – by authorizing the Paul Coverdell National Acute Stroke Registry and establishing a clearinghouse to provide technical assistance to states and share best practices in stroke treatment and prevention; and

- **Educate medical professionals** – through innovative programs that train medical personnel in the use of newly-developed diagnostic approaches, technologies, and therapies for the prevention and treatment of stroke.

Call to Action!

Advancing the STOP Stroke Act remains a priority for the American Heart Association and the American Stroke Association, but we need your help. It is important that your members of Congress hear from you about this important issue. Please call or write your Senator and Congressmen, asking that they co-sponsor the STOP Stroke bill. Senator Dick Durbin can be contacted at <http://durbin.senate.gov/> and Senator Barack Obama can be reached through <http://obama.senate.gov/>. Their Washington DC offices:

Senator Dick Durbin 332 Dirksen Senate Bldg Washington, D.C. 20510 (202) 224-2152 (202) 228-0400 - fax	Senator Barack Obama 713 Hart Senate Ofc Bldg Washington, D.C. 20510 (202) 224-2854 (202) 228-4260 fax (202) 228-1404 TDD
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The AHA web site www.americanheart.org/ has a Legislative Directory (in the Advocacy: You're the Cure section) that lets you identify your elected officials by zipcode and link to their web sites to email them directly.

You can also make a difference by visiting www.researchsaveslives.org to ask your legislator to support funding for heart disease and stroke research.

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Illinois Mom Runs Marathon for Her "Hero"

Two-Year-Old Stroke Survivor is Inspiration for Mom to "Train To End Stroke"

"We used to joke, 'oh, she's going to be a lefty,'" said Grayslake resident Judy Bergman of her then-four-month-old daughter, Noelle, when she began reaching for objects with her left hand. After a smooth pregnancy and birth, Bergman and her husband, Rich, were excited to welcome their second child in February of 2003. But as the months progressed and Noelle never used her right hand, her parents started to worry and consulted their pediatrician, who referred them to a physical therapist and finally a neurologist. The conclusion was startling: before she was even born, Noelle had suffered a stroke that affected the right side of her body.

"I was in shock," said Bergman, "I didn't realize a child could have a stroke."

Even though stroke is considered an older person's disease, the statistics indicate otherwise. According to the Children's

Hemiplegia and Stroke Association, childhood stroke occurs in about six of 100,000 children, and claims the lives of about 12 percent of those affected. However pediatric stroke occurs most frequently in infants before birth or shortly after birth, with an incidence rate of 1 in 5,000 babies.

Noelle was officially diagnosed at eight months, and her physicians assembled a team of physical, occupational and speech therapists to begin early intervention. Today, two-and-a-half-year-old Noelle receives therapy four times a week and is progressing well. "Noelle has movement of her right arm, but still not her fingers. She'll open her right hand with her left hand and will try to use it," Bergman said. "it's encouraging."

While steady, Noelle's progress is not enough for her mom. Bergman has committed to raising funds for pediatric stroke research through the Train to End Stroke program with the American Stroke Association, a division of the American Heart Association. While she claims she is not a runner, Bergman has committed to complete a half-marathon in Phoenix in January 2006 and has been training with a local Train to End Stroke team every weekend. She hopes to raise \$3,600 to fund stroke research and raise awareness.

"So many kids are not being diagnosed until later. Early detection and intervention are key," Bergman said. "I'm hoping to increase awareness of childhood stroke so parents can recognize the symptoms early and work with their doctors."

Bergman has arranged that all of her funds be earmarked for pediatric stroke research with the American Stroke Association. Those wishing to support her fundraising efforts may make an online donation at www.teamchicago.kintera.org/az06/jbergman.

"Noelle and other children like her are true heroes," Bergman said. "They spend hours in therapy each week learning to do simple tasks that others take for granted."

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Completing a Marathon is a Life-Changing Event....So is Having a Stroke

The American Stroke Association is recruiting people who aspire to complete a full- or half-marathon for Train to End Stroke, a team marathon-training program. Participants will train for four to five months with an experienced coach, while at the same time raising funds for the American Stroke Association's educational programs and research efforts. Participants who reach the assigned fund-raising goal will receive airfare, hotel accommodations and ground transportation to participate in marathons in California or Hawaii in June 2006.

Free Train to End Stroke information sessions will be offered throughout Metro Chicago in December and January, though aspiring marathoners from throughout the state are encouraged to participate. For more information on Train to End Stroke, please visit www.strokeassociation.org or contact Kristin Novak at 312-346-4675 or kristin.novak@heart.org.

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PACHS: Providing a Voice For Kids With Stroke



Do you or someone you know have a child who has suffered a stroke? You're not alone: PACHS, Parents' Association for Children with Hemiplegia and/or Stroke, is a support and information group that is here to help. Launched in 2002 by a mother of a young stroke survivor, today the group connects over 40 families from Illinois and Indiana with a network of doctors, therapists, service providers and researchers. To learn more about PACHS, please visit www.pachs.org or contact info@pachs.org

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Support Group Corner

Why join a support group? To have a positive impact and deliver most benefits, a group should help you take better care of yourself, cope with a disease and its after effects, manage stress or

depression, enrich quality of life and improve survival. A tall order!!!

Education-focused and professionally led groups, rather than emotion-based peer groups, can help its members feel and function better. Whether the group's professional is a nurse, therapist (OT, PT or Speech), case manager, social worker, psychologist, or a combination, the professional performs a valuable advisory function, pulls in the appropriate resources and guides the group to keep it on track.

Support Groups can be a source of practical information not provided elsewhere – healthcare-related, community based, or common experiences and adjustments shared by others.

Please share your experiences – Support Group program ideas, the best speakers or the most valuable info. 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.

Sources:

- Consumer Repts on Health. 2000 Nov; healthcaresavvy
- Disabil Rehabil. 2004 Sep 16;28(18):1067-78
- Disabil Rehabil. 2000 May 10;22(7):330-6
- Stroke. 2003 Mar;34(3):801-5

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On the Web

The goal of this periodic column is to help our fellow "civilians" find useful and reliable online medical and health



information that isn't written in "medicalese" and is credible, timely and safe. Here are a few Web sites you can count on:

American Heart Association <http://www.americanheart.org>
 The official site of the AHA has a link to the American Stroke Association (ASA) (<http://strokeassociation.org>). The ASA site provides a broad spectrum of information –including reducing risk, accreditation programs that help identify hospitals, rehabilitation facilities and healthcare professionals providing quality care for stroke patients, Life After Stroke, and special sections on African Americans and stroke, caregiver subjects, and en espanol. Advocacy topics are primarily concentrated on the parent AHA site <http://www.americanheart.org> in the "Advocacy: You're the Cure" section. Resource Center for Advocates' "Learn Our Issues" is a great place to start learning about the public policy issues that affect you personally. About these sites the Medical Library Association says: "Sponsorship is clear, content is factual, and policy briefs are clearly identified as such." It's clear and easy to navigate and read. Aesthetic, Logic and Content each rate 4 stars. ★★★★★

If you want to know about a medication you've been prescribed, for comprehensive info go to <http://www.nlm.nih.gov/medlineplus/druginformation.html>

I typed in Vasotec, a common brand of blood pressure medication, as an example. It gave me the following on Enalapril, the generic form of Vasotec:

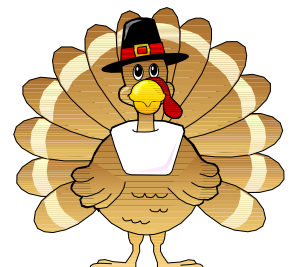
Contents of this page:

- [Why is this medication prescribed?](#)
- [What side effects can this medication cause?](#)
- [How should this medicine be used?](#)
- [What storage conditions are needed for this medicine?](#)
- [Other uses for this medicine](#)
- [In case of emergency /overdose](#)
- [What special precautions should I follow?](#)
- [What other information should I know?](#)
- [What special dietary instructions should I follow?](#)
- [Brand names](#)
- [What should I do if I forget a dose?](#)
- [Brand names of combination products](#)

The site is completely bi-lingual (Spanish), it's reliable, consumer-friendly and easy to get around. Aesthetic, Logic and Content each rate 4 stars. ★★★★★

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SSEEО wishes you a happy and



SSEEО Update

healthy holiday season