

Sometimes proper terminology fits tightly or loosely, but other times, the terms do not apply at all. Terminology of the medical or rehabilitation fields is quite necessary to know in order to communicate effectively with your health care team. Guidance may be needed to learn what some of these terms mean for you and your loved one so that you can be well-informed. There are numerous resources on how to learn what you need to know from the internet, local library and health institutions. If you are not sure what it is you should know, ask your health care team what you need to know that will help you make the right decisions for you and your loved ones. The adage, "knowledge is power", rings true.

The word 'disabled' means someone who is not able to do something. The word 'survivor' denotes that the individual was able to overcome an enormous disabling condition. Lobby Days in Washington DC proved that the disabled or survivors due to heart disease or stroke are in fact very able. Not only did they survive a tragedy in incredible ways, but now demonstrate all too well how fulfilling life can be. In some cases, the same individual had suffered a series of heart attacks and strokes and had even undergone chemotherapy due to a cancer diagnosis. This does not even include the other life events we experience that can be good, bad or ugly. I departed from DC with a true admiration for these amazing brave survivors and caregivers alike and gained a new perspective. There is a very powerful force behind us all that comes from deep within that compels us to make a difference, learn all there is to know and create positive change. It enhances our wisdom, renews our hope and moves us into action. This leads to 'empowerment'. One evident side effect of this is improved 'quality of life'. Learning terminology, being active with the American Heart Association, finding resources and joining forces with other survivors and caregivers are some actions that lead to empowerment. By the way, caregivers are survivors too.

Maria Ugarte-Ramos is a freelance writer, social worker and caregiver of her husband, Fausto. She is the President of FAMA Enterprises, LLC.

she'll come along to tell her story along with the other inspiring survivors I met last week. "The idea that I might have made a difference will make Mothers Day especially sweet this year. Through all of this experience, we've learned to appreciate things so much more, still there are so many families much more affected (by pediatric stroke) than ours."

Sarah Exley is a communications specialist who also volunteers for the American Heart Association - Greater Milwaukee to raise awareness for pediatric stroke.

Kristyn Adams is a reporter for the West Bend Daily News in Wisconsin. This article was originally published on May 10, 2008.

Strike Out Stroke Day!

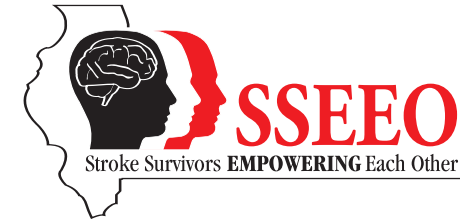
By Maria L. Ugarte-Ramos

On June 1, a collaborative effort between SSEEO and the Alexian Brothers Neuroscience Institute held the third annual "Strike Out Stroke Day". The baseball game, held at Alexian Field in Schaumburg, was dedicated to help raise awareness for stroke prevention. A health fair offered blood pressure screenings while representatives from SSEEO, American Heart Association, Alexian

Rehabilitation Hospital and Alexian Brothers Neuroscience Institute provided informative brochures about health and services.



We would like to thank our sponsors for believing and supporting us in our mission.



WRITTEN FOR STROKE SURVIVORS BY STROKE SURVIVORS

Notes from John and Marylee

By John and Marylee Nunley

As the newest members of the SSEEO Steering Committee, we are still learning about the SSEEO purpose and its impact on stroke survivors. John's stroke occurred in September of 2001, the day before the national tragedy. We could not envision what the post-stroke journey ahead of us would be like. Although John's recovery has been very good, we still face daily challenges as a result of the stroke. Since our marriage in 1996, John has struggled with multiple health issues, but always recovered. Stroke is different!



As many of you know, there is a definite shift in friendships following stroke. With so much therapy and other post-stroke treatments, we were kept very busy for a long time without much time to think. We have always enjoyed our support group and creating new friendships. At the two-year mark following John's stroke, Marylee read an article about a camp for people with aphasia and it sparked an idea to provide a camp for stroke survivors. Church camps are common practice in our family with family members who directed camps for children with Cystic Fibrosis. Coupled with the support of Dr. David Wang from the Illinois Neurological Institute at OSF Saint Francis Hospital and his staff, Retreat and Refresh Stroke Camp was born in September of 2004.

This past January, we began offering the camp to interested sponsors (hospitals, rehab facilities and communities) at the national level. This "Camp In A Box", as we fondly call it, is everything you need for a successful weekend. As we travel through our journey, we look forward to meeting many of you throughout the year, hearing your stories and sharing ours.

Stroke Survivors Empowering Each Other (SSEEO) c/o American Stroke Association

208 S. LaSalle, Suite 900
Chicago, IL 60604
Christine Sumida, Coordinator
Phone: 312-476-7336
Fax: 312-346-7375
christine.sumida@heart.org
www.strokeassociation.org

For questions or comments about the SSEEO Newsletter or if you want to share your story, please contact Christine Sumida.

Retreat and Refresh Stroke Camp

By Marylee Nunley

Imagine you have had a stroke and have been in your own world or rehab working hard towards recovery. You've lost a few friends and even family members don't come around as much as they used to right after the stroke. In your quest for complete recovery, you discover that "full" recovery might not be a reality. Now imagine you get an invitation to attend a weekend camp for survivors and caregivers that will take you away from your routine. You learn

about new treatments. You become acquainted with a group of new friends who welcome you and understand what you have been through.

The amazingly fun weekend is a mixture of education, socialization, support and relaxation. The education might be on new treatment modalities, a workshop with a nutritionist or speech therapist, a Q & A with a neurologist or information on traveling with a disability. Socialization occurs by using rhythm instruments, conversations, games, crafts, fishing, boating and roasting marshmallows around a campfire. A strong and encouraging support system is in place from the initial introduction throughout all the activities. Most importantly, survivors and caregivers have the opportunity to speak with others like themselves in a safe and nurturing environment about their challenges, triumphs and solutions. The outdoor setting is always conducive to relaxation whether it is yoga, music, boating, reading, singing, massage, manicure or pedicure. With all this pampering, you are sure to leave refreshed.

Retreat and Refresh Stroke Camp is a non-profit organization committed to improving the quality of life for stroke survivors and their caregivers and families. We are seeking sponsors' who have survivors and caregivers' best interest in mind. The sponsors need only provide volunteers and the fee for camp. For more information, please contact Marylee Nunley at 309-693-2375, marylee425@comcast.net or visit us at www.strokecamp.com.

Aphasia Laboratory Study

By Dirk den Ouden

Northwestern University's Aphasia and Neurolinguistics Research Laboratory, led by Prof. Cynthia K. Thompson, is one of the leading laboratories in the country for studying language processing and recovery after stroke in the human brain. The Laboratory seeks healthy individuals for its Functional Magnetic Resonance Imaging (fMRI) and eye-tracking studies. fMRI is a non-invasive means of measuring and localizing brain activation, while eye-tracking is a method by which language processing is studied by measuring eye movements during language tasks. Participants are compensated for their time. In addition, the lab is always looking for stroke survivors with language problems (Aphasia), to participate in our treatment studies. If you are interested, please contact the lab at

847-467-7591 or email m-cosic@northwestern.edu (Mary Cosic). The lab is based in Evanston, Illinois.

ReVOC Emerges

By Maricela Hernandez

ReVOC is an emerging grassroots group of Vocational Rehabilitation (VR) clients, consumer advocates and other allies. ReVOC stands for renewing Vocational Opportunities for Consumers and provides a voice for all people with disabilities interested in improving access to good paying jobs, quality VR services, and broader social justice. In short, we seek to end the massive economic deprivation, poverty and unemployment of all people with disabilities.

Maricela Hernandez is the Education and Outreach Coordinator at Access Living (www.accessliving.org), a non-residential Center for Independent Living for people with all types of disabilities. The services promote the independence and the inclusion of people with disabilities in every aspect of community life. All of the services are provided at no charge. For further information about ReVOC, please call (312) 640-2185 TTY (312) 640-2167 or email mhernandez@accessliving.org.

Legislative Beat

By Fausto Ramos Gómez

This past April, over 700 individuals representing every state in the U. S. convened on Capitol Hill to lobby their legislature to support our efforts. Over 60 Illinois representatives collectively visited with the legislative aides of Senators Obama and Durbin. The two key asks included: increased funding for heart disease and stroke research, and prevention programs and support of the new legislation for the FIT Kids Act, which addresses childhood obesity through improving physical education in schools. A small group of us from the 9th Legislative District met with Congresswoman Jan Schakowsky. I had the opportunity to share my personal story of how the stroke has impacted my life. Representative Schakowsky's thoughtful questions



reminded me of her commitment and showed how she really cares about her constituents. All in all, we were reassured that our presenting issues are indeed top priority items for our federal legislators. Our lobbying efforts were successful!

The Primary Stroke Center Bill (HB4699), now Senate Bill 2708, with place holder language, passed the Senate in late May. The Bill would allow for designation of Primary Stroke Centers in Illinois and thereby, would allow patients and their families, as well as first responders, to make better informed decisions when responding to a stroke emergency. The bill is in need of additional amendments on the Senate side and all of us along with the American Heart Association/American Stroke Association are working diligently with key stakeholders to finalize the bill language. We hope to amend the bill with agreed-upon language this summer and will seek its passage in the fall veto session, which will be held on November 12, 13 & 14 and November 19, 20 & 21. *SSEE members: please set aside these dates to join AHA staff in Springfield to push for passage of the legislation.* In the meantime, **please help by sending a letter to your State Senator to co-sponsor the Primary Stroke Center bill today!** We need your help!

Fausto Ramos Gómez is a survivor, member of the SSEE steering committee and chairperson of the Advocacy Committee.

Mom on a Mission

By Kristyn Adams

Sarah Exley of Germantown couldn't find a doctor who could explain her infant daughter Avery's symptoms. The otherwise bright-eyed, content and seemingly normal baby was slow to move on the right side of her body, her right hand usually tightly closed. After a year of inquiries, footwork, phone calls and exams, a doctor accurately provided the shocking diagnosis. Avery had suffered a pediatric stroke before her birth.

Exley's relief at finally having a diagnosis, combined with a mother's dismay, stirred her to action. Knowing her daughter's condition to enable further her treatment was a positive, yet the diagnosis took more than a year. Exley, along with the medical professionals she consulted, knew little about pediatric or childhood strokes. That motivated Exley to board a plane to Washington D.C. to lobby for her daughter and the future of other children.

The opportunity to face those of influence presented itself through the You're the Cure Organization and the American Heart Association's National Lobby Day. During a two-day event in late April, Exley joined 700 participants representing all states, including 20 advocates from Wisconsin.

Recognized as a strong advocate for children's issues, Wisconsin Sen. Herb Kohl made an unexpected appearance during a speech Exley gave to other Wisconsin supporters. "I can't say enough about the experience," Exley said.

"As many people find out, you often don't actually meet with the elected officials; you meet with their assistants or their policy advisors," Exley said. "So we got in there, and guess who had to speak first? Me! I took a deep breath and spilled my guts."

"I had an awesome flyer with Avery's picture and story, and how increased NIH (National Institutes of Health) and CDC (Center for Disease Control) funding could help children like her, and guess who walks in as I'm talking? Yep, Senator Herb Kohl," she said. "I just looked up at him and kept on going."

A mother still on a mission, Exley later spoke with Kohl about fundraising and pediatric stroke awareness. "Senator Kohl was amazing to talk to," Exley said. "I wasn't intimidated, but I was doubtful that any political figure would take time and really listen to me."

"But there he was and I was thrilled because I could tell he genuinely cared to hear every word I said," Exley said. "He was blown away by Avery's story, asked how she was doing now, and most importantly, said he'd support the increase in funding. It's amazing to feel like you've gotten through to someone, like they really get it."

In addition to Kohl, Sen. Russ Feingold and Reps. James Sensenbrenner and Gwen Moore attended the National Lobby Day event. Besides the opportunity to educate Wisconsin legislators on pediatric stroke and communicate with those on Capitol Hill, Exley found fellow advocates gave her a reason to return. "I cannot wait to do this again next year," Exley said. "Someday when Avery's old enough,

