

This new feature is intended to offer support, resources and assistance for caregivers and families. It may also help stroke survivors. Caregivers face challenges. They are advocates who share with their loved one the flood of emotions: shock, grief, anger, depression, sense of loss and stress caused by this life-changing tragedy.

Emotions are deep, complex and perplexing for healthy individuals. Add the suffering of a stroke and it can become devastating for the survivor, caregiver and family. The caregiver is suddenly positioned to be in a role unprepared to face a future with so many unknown factors. In most cases, lives are turned upside-down, dreams vanish into thin air and hopes, shattered. The management of the most basic daily living needs surge to the forefront.

The associated emotions following a stroke may be overwhelming, yet healthy to recognize. These feelings are significant because they affect so many aspects of our lives: family, work, education, hobbies, to name a few. They can be re-channeled so that they do not prevent one from having a satisfying life. The approach in how we deal with these sensations makes an enormous difference in the overall quality of our lives. The first serious consideration is professional counseling even if short-term for any turmoil one may feel. Some other effective ways to deal with the stream of emotions are: humor, journaling, exercise, doing our favorite things and setting up a strong support network, all familiar to the human experience. It is essential to find what works best for you and your situation.

It is a relief to hear, "life can still be fulfilling after a stroke." These words ring true as we all continue to look for ways to improve our lives through new therapies, new ventures and new friendships. Special moments transpire everyday as we remain optimistic that things will continue to evolve in the right direction, one step at a time.

## REMINDER: SSEEEO and ASA Telephone Conferences

Welcome to the first series of Conference Calls for the new year! These calls last approximately 60-90 minutes with the first 30-45 minutes in "listen only" mode. The lines then open for questions and conversation. All conference calls begin at 12:00 noon.

### February 29 Preventing Stroke in Women Dr. Phil Gorelick

Medical Director, Stroke Center at Alexian Brothers Hospital Network  
John S. Garvin Professor & Department Head, University of Illinois at Chicago

### March 14 Stroke Rehabilitation Road to Recovery Dr. Michael Berkowitz

Administrative Medical Director, Alexian Rehabilitation Services Affiliation with the Rehabilitation Institute of Chicago & Medical Director, Alexian Rehabilitation Hospital

### April 25 Endovascular Procedures for Stroke Atherosclerosis Dr. Tim Malisch

Medical Director, Interventional Neuroradiology Program  
Alexian Brothers Medical Center

### May 30 Intracerebral Hemorrhage and Stroke Dr. Szymon Sami Rosenblatt

Medical Director of Neurological Surgery, Alexian Brothers Medical Center  
Assistant Professor, Rush University Medical School, Department of Neurosurgery

**IMPORTANT CALL-IN INFORMATION:** Participation is free, but advance registration is required due to limited line availability. Please contact us at 1-800-677-5481 ext. 7438 and provide your full name(s), mailing address, e-mail address and telephone number.



Alexian Brothers Medical Center  
St. Alexius Medical Center  
Alexian Brothers Behavioral Health Hospital  
Alexian Rehabilitation Hospital

## SSEEEO UPDATE

STROKE SURVIVORS EMPOWERING EACH OTHER



## WRITTEN FOR STROKE SURVIVORS BY STROKE SURVIVORS

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Volume 4

Issue 1

### Inside This Issue

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**NEW** Caregivers' Corner  
Conference Call Reminder

## Notes from Maria

By Maria L. Ugarte-Ramos

### Welcome Christine Sumida

This past quarter, an ad hoc committee was formed to interview applicants for the newly created position of part-time SSEEEO coordinator. Christine Sumida proved to be the most highly qualified candidate and was selected by a unanimous vote. Christine has a strong knowledge base, possesses numerous talents and her skills complement this position well. She is passionate and highly motivated to help the SSEEEO community thrive and to support the voices of stroke survivors and caregivers. Christine has already taken a proactive approach in facilitating the efforts of the new partnership between the American Heart Association (AHA), American Stroke Association (ASA), SSEEEO and the Alexian Brothers Health System. Her responsibilities include supporting SSEEEO activities, enhancing SSEEEO's visibility in Illinois and strengthening SSEEEO.



Christine is the former Heart and Stroke Initiative Director of the AHA. Her role was to develop, implement and coordinate community-wide strategies, programs and services to position the AHA as the leader in cardiovascular

health issues. She also served as a staff leader on stroke issues and was an active participant at the National Institutes of Health annual conference and various other symposiums. Among her multi-faceted talents, Christine is skilled at implementing quality improvement initiatives, developing marketing strategies and increasing corporate participation to raise funds. Prior to this, Christine was the Senior Health Educator at McNeal Health Network and the Director of Medical Affairs for the American Cancer Society. Christine juggles her professional tasks while being a dedicated mom to her two young children, a supportive spouse and an efficient homemaker. Her knowledge, determination and positive energy will be true assets to the SSEEEO community.

Congratulations Christine and welcome, on behalf of SSEEEO and the AHA/ASA. We look forward to a very rewarding relationship!

**Stroke Survivors Empowering Each Other (SSEEEO)**  
c/o American Stroke Association  
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www.strokeassociation.org

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

## Treatments and Therapies for One-Sided Weakness/Paralysis

By Mary Kay Ballasiotes

I am the mother of a 10-year-old girl, who suffered a hemorrhagic stroke before she was born. As a result, she has right hemiparesis, and has not had full use of her right arm and leg since birth. In my quest to find the best treatment, the best doctors, the best specialists and the best therapies for her, I realized there wasn't a lot of information for pediatric stroke survivors, which is why I formed a group for families just like mine called *Childhood Stroke & Hemiplegia Connections of Illinois* ([www.csconnections.org](http://www.csconnections.org)) almost six years ago. Our group provides opportunities for families to meet with medical professionals in the greater Chicago area, as well as communicate with each other, all to benefit our kids. We have grown from six families to almost 70. Some drive from as far away as Wisconsin and Indiana to attend our meetings.

It was while sitting at one of our meetings last fall, listening to a wonderful presentation from therapists at *Milestones For Kids Success* ([www.milestones4kids.com](http://www.milestones4kids.com)) that I realized, "if these therapies and treatments are good for kids, why can't they be used for adult stroke survivors too?" The answer was that some of these treatments may be beneficial for adults with one-sided weakness, so I wanted to share them with our SSEEEO group. I do want to emphasize that not all of these will be beneficial for all stroke survivors and you should seek the advice of a medical professional before using or starting any of them. I also want to mention that this is not a comprehensive list. These are just a few of the treatments that have benefited children and may also help adult stroke survivors.

**Aqua Therapy**—The performance of activities in an aquatic environment to promote symmetry in the extremities for children with hemiplegia.

**Botulinum Toxin (Botox)**—Splinting has been a mainstay treatment for the prevention of limb deformity. Now, when combined with the use of botulinum toxin, the amount of time the limb is

splinted and even the extent of the splinting is reduced. Botulinum toxin is an injectable neurolytic, which is a nerve block that although temporary, may allow a window of time to improve strength and motor control.

### **Constraint-Induced Movement Therapy**

(CIMT)—Forced use therapy was developed by Dr. Edward Taub to improve arm and hand function in adults. It is now applied to children with hemiplegia. The high functioning arm and hand are gently restrained so the person has no option but to use their affected limb. More information on CIMT can be found on the American Stroke Association's website at [www.strokeassociation.org](http://www.strokeassociation.org).



**Electrical Stimulation** (Estim, NMES, RES, TENS, bio-feedback)—These are all names for different types of therapeutic electrical stimulation which, when applied externally, can act as a substitute or replacement for an internal electrical signal and cause several different beneficial reactions/effects in the body. These can help with muscle spasms, decreased range of motion, muscle re-education, spasticity and weak muscles.

**Kinesiotaping**—This method uses tape made of elastic strands wrapped in cotton to support the muscles in movement, relieve pain, remove congestions of lymphatic fluid or correct misalignment of the joints. It was invented by Dr. Kenso Kase, D.C., who believed that muscles and other tissues could be treated by outside assistance.

**Serial Casting**—A non-invasive procedure helps improve range of motion for standing and walking. The process involves placing a well-padded cast to immobilize a joint. The cast is applied and removed on a



weekly basis to gradually increase the range of motion of the affected joint.

Source: *Milestones for Kids Success, Downers Grove, Illinois*  
Dr. Deborah Gaebler-Spira, Rehabilitation Institute of Chicago

## Wii Helps Stroke Survivors January 2008

By Maria L. Ugarte-Ramos

Revolutionary Wii helps stroke survivors regain their strength. At least two rehab centers have begun using Wii for rehabilitation purposes for stroke survivors as well as patients with spinal cord injuries and other traumatic brain injuries. Wii, manufactured by Nintendo, allows players to mimic the actions of swinging a racket, bat or club, roll a ball down an alley or bring the left jab. It provides a natural, intuitive and realistic feel as if one were actually playing tennis, baseball, golf, bowling and boxing. Wii can also be played in the comfort of one's living room.



Rehabilitation professionals at The Ohio State University Medical Center recently began using the Wii system to assist patients in working on visual and cognitive skills, problem solving, balance, coordination, and upper and lower body strength and endurance. Robbie Winget, an occupational therapist, oversees the use of the Wii system at Ohio State's Dodd Hall Rehabilitation Hospital. "It really encourages patients to get engaged in their therapy. The games can be more

motivating than standard exercises. But this does not replace conventional therapy at all. It's one more way to meet specific goals associated with therapy," Winget said. Inpatients typically work with the video game system for about 30 minutes per day two to three times per week.

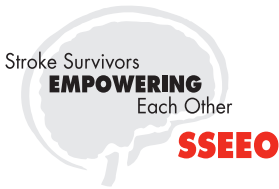
At the Sister Kenny Rehabilitation Institute in Minneapolis, Minnesota, they call it Wii-hab and patients are having some serious fun. The fact that patients are motivated marks success. It is significant because playing the game is a step toward life as usual. There are other advantages such as, retraining the body, regaining the ability to move and receiving real-time feedback on patient actions in a safe environment. The Sister Kenny Research Center is tracking patient success and may have results later this year.

Not only does Wii offer a variety of entertainment, information and communication channels, it provides stroke survivors information on its news or weather channels to improve brain function. Although not mainstream yet, Wii may revolutionize standard therapy protocols across the nation.

### About the Contributors

**Mary Kay** is a member of the SSEEEO steering committee. Her third child suffered a stroke before she was born and has right hemiparesis (a form of cerebral palsy) as a result. Mary Kay is the founder and president of a greater Chicago support and information group for families with children just like her daughter. The group, "Childhood Stroke & Hemiplegia Connections of Illinois", began in April 2002 and consists of over 70 families who help each other cope with raising a young stroke survivor.

**Maria** is a social worker, writer and caregiver of her husband, Fausto Ramos Gómez. Both serve as members of the SSEEEO steering committee. Fausto suffered a stroke in 2001 while undergoing back surgery. At the time of the stroke, Fausto was in the midst of obtaining a PhD in the politics of education from the University of Chicago. He was an education officer for a foundation, a university professor and a research scientist. Fausto is permanently disabled with aphasia and right-sided weakness.



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St. Alexius Medical Center  
Alexian Brothers Behavioral Health Hospital  
Alexian Rehabilitation Hospital

## **Stroke Survivors Empowering Each Other (SSEEO), the American Stroke Association and Alexian Brothers Hospital Network**

invite you to join the monthly call-in support group for  
Stroke Survivors throughout Illinois!

*The goal of the SSEEO Toll-Free Telephone Stroke Support Group is to build community, provide support and share information by connecting survivors, caregivers, health professionals and other stroke stakeholders. The calls will last approximately 60-90 minutes. The first 30-45 minutes will be in "listen only" mode for our guest speaker's presentation. We will then open the lines for questions and conversation. Please don't forget to register by following instructions below.*

### **Upcoming Topics: Medical Updates in Stroke 2008**

#### **Preventing Stroke In Women, call at Noon Friday, February 29, 2008**

Dr. Phil Gorelick is the Medical Director of the Stroke Center at Alexian Brothers Hospital Network and John S. Garvin Professor and Department Head at the University of Illinois at Chicago.

#### **Stroke Rehabilitation Road to Recovery, call at Noon on Friday, March 14, 2008**

Dr. Michael Berkowitz, Administrative Medical Director for the Alexian Rehabilitation Services Affiliation with the Rehabilitation Institute of Chicago and Medical Director Alexian Rehabilitation Hospital.

#### **Endovascular Procedures for Stroke Atherosclerosis, call at Noon on Friday, April 25, 2008**

Dr. Tim Malisch is the Medical Director for Interventional Neuroradiology at Alexian Brothers Medical Center.

#### **Intracerebral Hemorrhage and Stroke, call at Noon on Friday, May 30, 2008**

Dr. Szymon Sami Rosenblatt is the Medical Director for Neurological Surgery at Alexian Brothers Medical Center and Assistant Professor at Rush University Medical School Department of Neurosurgery.

Leading and national experts from the ABHN Stroke Program will share the latest advances in acute stroke treatment, stroke prevention and rehabilitation. You will also learn intervention and the prevention and treatment of both hemorrhagic and ischemic stroke. Our stroke program is one of the most comprehensive in Illinois. We thank you for your participation and we look forward to lively discussions about stroke.

***IMPORTANT CALL-IN INFORMATION: Participation on the calls is absolutely free but advance registration is required due to limited line availability. Please contact us at 1-800-677-5481 ext. 7438 and provide the following information: First and last name(s), mailing address, e-mail address and telephone number. We will get back to you with an 800 call-in number and pass code which will allow you to access the conference. For those who wish to attend the support group in person, please join us at Alexian Brothers Neuroscience Institute at 800 Biesterfield Rd in Elk Grove Village, IL 60007 Eberle Building Suite 610. All welcome!***