



The National Aphasia Association
 a•pha•sia (uh-fay'-zhuh) n. An impairment of the ability to use or comprehend words, usually acquired as a result of a stroke or other brain injury.



Celebrating Our 20th Anniversary ~ 1987-2007

July 2007

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NEWSLETTER

MESSAGE FROM THE NEW PRESIDENT OF THE NAA

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Executive Director
- Rachel Quimby,**
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Fundraising Consultant



The wonderful news is that the Congress of the United States (both House and Senate) voted to make June Aphasia Awareness Month. Please use this opportunity to let your friends and loved ones know that, slowly but surely, we are building a constituency for people with aphasia and increasing awareness among the general public of this condition.

We are still seeking someone of renown to become a spokesperson for people with aphasia. We strongly believe that the most effective person to do this would be someone whose life has been personally touched by aphasia. Names that have been mentioned as possibilities include Alan Alda, Julie Andrews and Dick Clark. If you know of anyone who might be appropriate, and better yet if you have a way to reach them, please let us know at the NAA, and we will work with you to try to convince them to become the public face of aphasia.

We are happy to report that we are increasing our network of State Representatives so that we can better meet the needs of persons with aphasia and their families around the country and in Canada. We need to increase the number of Aphasia Community Groups as these are a wonderful resource and a place to gain support. Please let us know of additional groups in your area or if you are interested in starting a group we can assist you.

Have a safe and enjoyable Summer!

Barbara C. Martin
President

IN THIS ISSUE:

HISTORIC EVENT FOR THE NAA	2
STAMP CAMPAIGN CONTINUES	2
HAPPY HOUR EVENTS	3
APHASIA AWARENESS MONTH ACTIVITIES	4
STROKE OF GENIUS	5
NEWS AND NOTES	6&7

HISTORIC EVENT FOR THE NAA AND PERSONS WITH APHASIA!

Congress Proclaims June National Aphasia Awareness Month!



Washington, DC-

On Wednesday, June 27th, the US Senate approved a resolution declaring June 2007 National Aphasia Awareness Month. S Res 256, sponsored by Senator Joseph R. Biden Jr. of Delaware, and cosponsored by Senator Tim Johnson of South Dakota, was passed by unanimous consent. A day later, in the House, Congressman Edward J. Markey of Massachusetts was the sole sponsor of H Res 523, which also passed unanimously.

Dr. Paul Rao, Speech Language Pathologist, member of the National Aphasia Association (NAA) Board and Vice President of National Rehabilitation Hospital, sought and received the NAA Board's endorsement to pursue a resolution in the House and the Senate declaring June 2007 as Aphasia Awareness Month.

Under the legislative auspices of Senator Tim Johnson's office, the NAA was able to craft a resolution that describes the cause and effects of aphasia and the need to increase public awareness of this silent disability.

These Congressional Resolutions are now part of the Congressional Record and can be used as advocacy tools to increase aphasia awareness throughout the year. The National Aphasia Association is indebted to Senators Biden and

Johnson and their legislative staffs and to Congressman Markey and his legislative staff in bringing this resolution to full fruition in June of 2007.

The NAA encourages everyone to write a letter to the sponsors of the resolution, thanking them for devoting their time to this important issue.

About The National Aphasia Association

The NAA's mission is to educate the public to know that the word aphasia describes an impairment of the ability to communicate, not an impairment of intellect. The NAA makes people with aphasia, their families, support systems, and health care professionals aware of resources to recover lost skills to the extent possible, to compensate for skills that will not be recovered and to minimize the psychosocial impact of the language impairment.

We are pleased to report that this information will be featured in upcoming issues of The ASHA Leader, The American Stroke Association's magazine "Stroke Connection" and the National Stroke Association's "Stroke Smart" magazine. We thank our colleagues for including us in their publications.

STAMP CAMPAIGN CONTINUES

Spread the word about Aphasia!

With enough letters from all 50 states, we can convince the US Postal Service to issue an aphasia postage stamp.

Go to—<http://www.aphasia.org/stamplate.htm>

Print and send a stamp letter at

<http://www.usps.com/communications/organization/csac.htm>

HAPPY HOUR EVENTS HELD IN THREE LOCATIONS

NASHVILLE, TENNESSEE

The first annual NAA Happy Hour benefit was held in Nashville, TN on June 18th on the patio of the Dan McGuiness Irish pub. The heat and humidity of Tennessee did not dampen the spirits of the 20 guests that stopped by to eat, drink, make merry and contribute money to support the work of the NAA and honor Aphasia Awareness Month. Many thanks to Wanda Webb and Lee Ann Golper for organizing this fabulous event!



MONTCLAIR, NEW JERSEY

Speaking of Aphasia hosted approximately 20 contributors at its Happy Hour Fund-raiser for the NAA on Tuesday, June 26th. *Just Jake's*, a popular bar in Montclair, New Jersey, provided one hour of non-stop energy via great food and drinks, while the attendees mixed and mingled in a casual, relaxed atmosphere. Other customers at the bar were curious about our "Ask Me About Aphasia" buttons, leaving with good information, and an impression that was definitely positive about what it is like living with aphasia. Happy Hour, and additional aphasia bracelet and button sales raised almost \$450 for the NAA. Many thanks to Shirley Morganstein and Marilyn Smith for organizing this great event!

NEW YORK CITY, NEW YORK

NYC hosted the Fourth Annual Happy Hour Benefit at Opal Bar. In spite of the torrential rain and blackout, 50 people came to socialize, drink, eat and support the NAA. There were fabulous raffle prizes including several restaurant gift certificates and tickets to a Mets baseball game. We sold "Ask Me About Aphasia" buttons, tote bags and displayed some of the materials that the NAA has available. A great time was had by all! Special thanks to Josh Roth and Caren Dranoff for organizing this successful event! We are especially grateful to Josh who developed the concept of the "Happy Hour" and has executed it beautifully.

CLICK HERE TO VIEW PICTURES FROM THE EVENT:

If you can't see the pictures in this email, click here to see it in a web browser:

<http://www.kodakgallery.com/l.jsp?c=vcomszg.5flp069c&x=1&y=lg13j1>

Aphasia Awareness Month Activities Around The Country and in Canada

The Aphasia Group at Atlantic Rehabilitation Institute in NJ had a very successful “Tell 10 people about Aphasia “ Day. They all wore aphasia t-shirts and buttons and displayed several of the NAA informational materials. They collected over 50 signatures to support the Stamp Campaign and sold aphasia wrist bands. They were interviewed by a reporter for an article in The Daily Record for Morris County, NJ which appeared in the paper in early July.



The Adler Aphasia Center in Maywood, NJ had a successful “Open House” event in June. The theme was “Giving Aphasia a Voice In the Community.” There were activities, opportunities to interact, information provided as well as entertainment.

The Stroke Education Network of NJ and Kean University Department of Communication Disorders and Deafness sponsored the Fifth annual conference on Living with Aphasia. Speakers included Mike and Elaine Adler, Karen Tucker, Executive Director of the Adler Aphasia Center, Ginette Abbanat and Karen Castka, Speech pathologists from the Adler Aphasia Center, Joseph Amoroso from the NJ Department of Human Services-Office of Information and Assistance Services, and Marilyn Certner Smith, co-founder of Speaking of Aphasia, LLC. The NAA was an exhibitor at the event which drew over 60 people on a Saturday morning.

Congratulations to the University of Michigan Aphasia Program which celebrated its 60th Anniversary with many events around Michigan including a Gala Benefit and screening of the movie “The Way Back Home” starring Julie Harris.

The Rehabilitation Institute of Chicago held a workshop for people with aphasia, their families, and friends called “Connections.”

An Aphasia Walk-A Thon was sponsored by the Aphasia Advocacy Foundation and was held in Manchester, NH.

The Long Island University, C.W. Post Campus, kicked off their Aphasia Center Summer Program In June. It is six weeks of socialization, education and communication for people with aphasia and co-survivors. NAA Executive Director, Ellayne Ganzfried, was invited to welcome the attendees at the 1st session.

The California Aphasia Center had a 3-mile “Walk to Talk” benefit in Oakland California. People were invited to Run/Walk/Roll around Oakland’s Lake Merritt.

Southern Ontario, Canada celebrated Aphasia Awareness Month with many events around Ontario

A New York Regional Aphasia Conference “A New Beginning” was held in June and sponsored by the International Aphasia Movement, Rehabilitation Department-Saint Vincent’s Hospital, The family of Martin Bennis, and the New York Aphasia Group.

The 29th Annual Aphasia Luncheon was held on June 11, 2007 in the Pavilion of the Rusk Institute of Rehabilitation Medicine. The annual event was sponsored in part by the Hospital Auxiliary of the NYU Medical Center and hosted by Dr. Martha Sarno and the staff of the Speech-Language Pathology Department. This year, 46 individuals with aphasia and their families/caregivers who had received speech therapy services at the Rusk Institute in the past attended the luncheon. Two members of the Aphasia Community Group program, Joel Fields and Mona Zamdmer, gave a talk about their experience of living with aphasia.

Aphasia Awareness Month Activities Around The Country and in Canada -continued-

The Boston University Aphasia Community Resource Center at Sargent College sponsored the “Stroke of Genius” music and film benefit at the Brattle Theater. (See below)

Stroke of Genius; a concert & documentary at The Brattle Theater

The Aphasia Center at Boston University's Sargent College sponsored the '*Stroke of Genius*' documentary at the Brattle Theater in Harvard Square/Cambridge, Ma., June 14th, 7 PM. The film, directed by Bahman Soltani, won a silver medal at the Park City Music Film Festival. It's an inspiring look at how, with love and perseverance, one man turned his tragedy into blessings for his community, his family and himself.

The evening was also supported by the National Stroke Association and the National Aphasia Association.

Here is a review by Jerry Kaplan of the BU Stroke Group:

June 25, 2007

“Stroke of Genius,” an extraordinarily moving evening of music and film, was presented at the Brattle Theater in Cambridge, Massachusetts on June 14th. Singer/songwriter Marc Black collaborated with creative advertising executive Dan Mountain on an album of songs. Mr. Mountain, who sustained a stroke in 2003, lay in a coma for three weeks. After his family was told there was virtually “no hope for meaningful recovery,” he was taken off life support and sent home to die. That’s when he woke up.

Over the next weeks and months, Mountain began to utter words and phrases which Black found startling, mystical, and poetic. He put these words to music and the result was “Stroke of Genius.”

In addition, Black contacted his friend, filmmaker Bahman Soltani. Soltani spent time with Mountain and his family, and created a documentary, also entitled “Stroke of Genius,” which chronicles Mountain’s journey through stroke recovery.

*Marc Black and Mike Esposito performed many of the songs from the album, in addition to other pieces. The combination of Black’s music and artistry on the acoustic guitar, Esposito’s work on the guitar (and a bicycle wheel!), and Mountain’s lyrics made for a powerful evening. Soltani’s film captures a family’s **hope and faith** in the midst no hope from the medical community. Mountain, himself, is the calm at the center of this tempest. He presents extraordinary dignity in his struggle to regain his physical and verbal skills. And he does so with humor, spirited resolve, and an inner peace for whatever the future may hold.*

“Stroke of Genius” is an extraordinary program. Inspirational without being preachy, it is a testament to the power of hope and the resilience of the human spirit.

*Jerome Kaplan
Speech-Language Pathologist*

To see a trailer and hear some of the music go here: <http://marcblack.com/index2.html>

The NAA is partnering with Marc Black to have a National Tour of Stroke of Genius. We are seeking support from individuals, aphasia groups, universities, etc all around the country who would like to have Marc perform his incredible songs and screen this ground-breaking movie. We need you to provide a venue and/or local support. Please contact the NAA at (800) 922-4622 or naa@aphasia.org to learn more about how to participate.

NEWS AND NOTES

⇒Aphasia is featured in June 19th edition of The ASHA Leader. There were several articles related to aphasia in The Leader including one by NAA Advisory Council member, Linda Carozza, and one written by NAA Executive Director, Ellayne Ganzfried which highlighted NAA President, Barbara Martin's heartfelt story. The transcript of the article follows:

Barbara Martin: Living Well With Aphasia

by Ellayne S. Ganzfried

More than a million Americans have aphasia and approximately 20% of the more than 750,000 Americans who suffer a stroke each year will experience aphasia. Despite these numbers, aphasia typically is not recognized or understood—even by some health professionals—compounding its devastating consequences. Too often people with aphasia are discharged from a hospital without knowing their condition has a name or that they can improve with time, speech-language treatment, and/or community support.

The National Aphasia Association (NAA), celebrating its 20th anniversary, works to dispel the lack of awareness that typically surrounds aphasia. An extraordinary example of the successful treatment NAA promotes is NAA President Barbara Martin, who embodies the concepts of hope, survival, and passion. In 1984, at the age of 45, she suffered a stroke while on a family vacation in Greece; she spent one month in acute care and three months in Burke Rehabilitation Hospital in White Plains, N.Y. Martin was extremely impaired both physically and communicatively, unable to move her right side, sit up, or say a word.

Martin credits much of her success in recovering communication skills to speech-language pathologist Mary Wagner, who worked with her at Burke and continued to see her five times each week at home for two years. (It is important to note that in those years, insurance coverage for speech-language treatment may have been more comprehensive.)

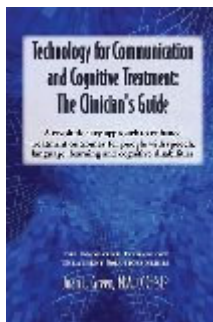
Martin progressed slowly but persevered. She drew motivation from her husband, Dan, her three children, and the many friends who supported her throughout recovery and who continue to do so today. Only five months after the stroke, Martin challenged herself by traveling into Manhattan alone to meet friends for lunch and a visit to the Metropolitan Museum of Art. To help navigate the trip, she carried a card listing her destination and explaining her impairment. Further testament to Martin's spirit was her return to work as a high school teacher two and a half years after the stroke. She arranged a manageable schedule, teaching two English and drama classes for the next 13 years.

Eighteen years ago, along with a friend who also had aphasia, Martin founded an aphasia support group at Burke Rehabilitation Hospital, where she received her own rehabilitation. She continues to facilitate this weekly group. According to Martin, the 15 participants "give me as much as I give them." She also leads a book group at the King Street Nursing Home in Westchester, and is taking a global politics class at New York University. Not bad for a person who was told she would never speak again!

NAA was fortunate to meet Martin about 12 years ago and recognized her enthusiasm and skills. Martin joined the Board of Directors and chaired NAA's most important fundraising event. She has been honored for her dedication and commitment to NAA and the aphasia community.

Last year Martin became president of the NAA and the association has thrived under her leadership. She speaks about aphasia at every opportunity, and she and her husband are strong advocates. Her ideal is to have weekly support groups in communities all over the country. She is also seeking a national spokesperson for the NAA who will help raise awareness of the disorder and enable many more people with aphasia to lead happier, healthier, and more fulfilling lives. Barbara Martin exemplifies "living well with aphasia."

⇒ A new resource is now available to help people who have had strokes improve with the help of technology. Learn from Joan Green- a speech-language pathologist and NAA State Representative with over 20 years of experience using technology to help adults who have aphasia and other communication and cognitive challenges. Chapters in this 400 page comprehensive practical reference tool were peer reviewed by over 40 neuropsychologists, speech-language pathologists, occupational therapists, and assistive technology specialists .



Technology for Communication and Cognitive Treatment: The Clinician's Guide was just released! It highlights products and techniques that will help improve communication, learning, thinking and remembering. Information is included about specialized multi-sensory software , free interactive websites, a variety of technology tools and tips for the selection and customization of resources. Products that are included offer features such as voice recognition, text-to-speech, word prediction, study and organizational guidance, and drill and practice customized exercises. This valuable resource is now available and can be ordered at www.ittsguides.com for \$89.95.

The Clinician's Guide is organized in a way to help a wide variety of rehabilitation and wellness professionals as well as other family members as they help people with communication and cognitive challenges. This guide outlines a revolutionary approach to enhance treatment outcomes It is written to help all of us who are busy efficiently locate the most pertinent information. "Top picks" are presented based on settings (i.e. school, hospital, long-term care) as well as the communication areas being addressed (reading, writing, talking, listening and cognition and memory.) There are also many online resources grouped by profession (speech-language pathologists, occupational therapists, teachers, neuropsychologists, assistive technology specialists) as well as diagnosis (stroke, head injury, learning disabilities, autism, dementia.). Many resources which are described are free. No prior computer experiences is needed to benefit from the information. There is an index of products (256) and vendors (163) for quick access to the information you need most.

Free shipping is offered to those who type in "free shipping" as a coupon code by the end of July. Testimonials, the Table of Contents and sample chapters can be found at www.ittsguides.com.

⇒ **NEW APHASIA BUTTONS— \$3.00 EACH OR 2/\$5.00**

**TO ORDER,
CONTACT NAA AT
NAA@APHASIA.ORG OR (800) 922-4622**



⇒ **GoodSearch.com** is a new search engine that donates ad revenue, about a penny per search, to the charity its users designate. Use it just like any search engine, and it's powered by Yahoo!, so you get the same great results.

⇒ **SPEAKING OUT 2008** to be held June 19-21, 2008 at New York University. Stay tuned for program information and registration details. Call the NAA office at (800) 922-4622 for more information.

⇒ **Welcome to NAA New Board Member, Phyllis Putter Barasch.** We are thrilled to have Phyllis join the Board. She brings extensive expertise as both a speech-language pathologist and a business/financial consultant.

⇒ **Look for Caucus NJ with Steve Aduato to present "Families in Focus: Aphasia Parts 1 and 2"** airing between July and September on East Coast affiliate networks. Click on the link to view schedule. Featured participants are NAA President, Barbara Martin, Mike and Elaine Adler, Karen Tucker and Ginette Abbanat from the Adler Aphasia Center, Shirley Morganstein of Speaking of Aphasia, LLC and Dr. Ronald Lazar-Professor of Clinical Neuropsychology for the Neurological Institute at Columbia University. <http://www.caucusnj.org/caucusnj/upcoming.asp>