



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.



NEWSLETTER

March 2008

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MESSAGE FROM THE PRESIDENT OF THE NAA



As we look towards Spring, we are excited about the activities of the NAA. The Spring Benefit is around the corner and it promises to be a memorable event-I hope to see you there!

Registration and housing information for Speaking Out is now available on line. We are looking forward to an exceptional program and anticipate many attendees.

We are taking great efforts to update both our State Representatives and Aphasia Community Groups listings. Thanks to our dedicated volunteers who are contacting each representative/group to verify information and make necessary changes online. It is so important that the information be current and we ask you to try and let us know when there are changes. A nice side benefit of this project has been our ability to recruit some new state representatives when we have contacted someone who is no longer interested.

Plans are beginning for Aphasia Awareness Month in June. We are hoping to get Congress to pass the proclamation once again this year. We urge you to contact your local representatives to have them support the effort in your city/town or state. We will be placing a sample proclamation on our website for your use. Stay tuned for additional updates.

We appreciate your support and generosity-We could not achieve our goals without it! Together we can raise awareness of aphasia!

Best Regards,
Barbara C. Martin

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We got Mail!

My mother has aphasia - a severe case. Last night we had a major breakthrough, so exciting for her that it brought her to tears. I would really like to share it with as many people as possible, hoping that maybe someone else could benefit from what we learned last night.

It is my hope you could put this in your newsletter.

It is lengthy - I think people need to understand how severe her aphasia is and how awful the impact has been on her. Only then can one appreciate how wonderful this breakthrough is for her!

Thank you,

Susan Riddle

Susan Riddle

Twin Falls, Idaho

(article "Breakthrough" on page 3 and 4)

“Breakthrough”

My mother, 78 years old, went into the hospital for surgery 17 months ago to have an aortic aneurysm repaired. That surgery was successful, but a blood clot popped loose from somewhere, causing a stroke as they were wheeling her out of the recovery room. She recovered quite well as far as the physical impact of the stroke, but she was left with an extremely severe case of aphasia.



Mom went through therapy for months after the stroke, physical, occupational and speech therapy included. She got to the point she refused to go, and the speech therapist said it wasn't likely to improve beyond that point anyway. From then on, it has only been me working with her, using all I'd learned from watching her therapists, and from information available on the internet. A great deal of that information came via the NAA website and links they provided.

She has both expressive and receptive aphasia. I would estimate that 95% of what she says is jargon. I try to laugh with her and tell her she is speaking Martian. She can say

some of what I call “reflex” phrases, such as: “Hi, how are you?” “Come on in.” “I don't want any.” “I can't.” There are many phrases like this that just come out automatically. However if you ask her a question she cannot respond with an answer. If you ask her to say her name she gets a blank stare. She can play black jack and poker perfectly, but if you ask her to show you a king or a nine, she cannot do it. I made a communication book for her with pictures of stores, restaurants, drink choices and so forth. We use this as a way for her to show us where she would like to shop or eat, etc. When we go to a restaurant, I have a couple of pages in my purse with drink choices, and pictures of soup or salad to make those choices possible for her.

If Mom has a health concern, if something hurts or is not working right, she cannot explain it to us. There have been times we have taken her to doctors and they cannot figure out what is going on either because she is unable to tell them. If there is someone she wants to see or ask about, it is impossible to understand unless it happens to be someone she has a photo of in which case she can show us. We keep a multitude of photos there for her to use in that regard. However, we are never able to really know what she is asking about a specific person – we do the best we can to guess but often we just don't get it.

After having the stroke, she moved into an assisted living facility a few minutes from our home. When incidents happen where she lives such as someone moving in, someone moving out, someone getting hurt, or just something exciting that happened, she tries so hard to tell me about it. I can get a staff person to tell me about things that have happened that day, which sometimes helps me figure out what is on her mind. The other residents cannot communicate with her. For the most part they avoid her because they don't understand. I try to join her at mealtime often, to help her visit with others. I try to explain to them what her condition is, and that she loves visiting with them, even if they can't understand her. Once in a while someone makes that connection and they become friends, doing the best they can to communicate. But sadly enough, it seems that the few other residents who have really tried and have made that connection with her have either passed away or moved to another place.

She is a prisoner of aphasia in so many ways.

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("Breakthrough" Continued from 3)

The staff where she lives is wonderful and they have a lot of fun activities for the residents. One of those activities is Bingo and they play twice a week.

My mom has always loved playing Bingo. During the years after my dad retired, they spent winters in Arizona and she would play Bingo twice a week with her friends at a casino.

My mom won't participate in many of the activities because she can't communicate with others. But she wanted to try Bingo. I would go along to help her. She cannot process the information when numbers are called out. I would have to point to the number on her bingo cards and she would place the chips on the numbers. **When she had a Bingo she knew instantly, no matter what shape they were looking for whether it was a traditional Bingo, a square, blackout, etc. She can't say "Bingo", but she would say something to get their attention & let them know she had a Bingo.** However, she was embarrassed that she couldn't do it on her own and quit going.

I have worked with her on this hour after hour - day after day - month after month since her stroke. We would practice Bingo in her room. **It just never clicked no matter how hard we worked at it. No matter how slowly and frequently I called out a number, she could not process the information and find the number on the card.**

I have explained details of her condition at great length so you will realize how serious it is and how drastically it has impacted her life. Knowing this will help you appreciate the exciting and major breakthrough I'm about to describe.

Last night, my husband and I joined her for the monthly family theme dinner they have where she lives. **After dinner, in her room, she was showing me that the clock on her microwave needed to be reset again.** She can never remember how to do it. She wanted me to write down which buttons to push. So I showed her and wrote down the buttons, but she also wanted me to write down the numbers for the time. I did it for the current time and by looking at what I wrote, she entered it perfectly, no problem. Then I tried to explain that those numbers would be different every time based on current time. Then...it occurred to me that she had a little battery operated digital clock on her table. So - I got it through to her that all she had to do was pick up that little clock, carry it over to the microwave, and enter the numbers based on the time shown on that little clock! Piece of cake! (as long as that little clock keeps working!)

Then I had a brainstorm...after the clock incident, it hit me like a ton of bricks! We took her down to the room where they play Bingo, and pulled out all of the Bingo supplies, sat down and played Bingo with her. Sure enough - **all I had to do was SHOW her the little ball with the letter/number on it as I drew it out & called it.** She was able to play Bingo perfectly! No hesitation, no problem finding the numbers - she was very quick at it too! By the time we were through, the staff was all in there with us applauding her - they gave her a rose & some candy bars (their usual prize for winning Bingo games)! Mom was so happy that she started crying. I just can't tell you how much this means to her! **The staff will see that she always gets seated right next to whoever is running the Bingo game and they will simply show the ball to her as it's called out.** Now she can go play Bingo twice a week with everyone else! Such a simple thing - and such a little thing - for most people.

But for her - it is HUGE!

This was a very long story about a very simple little accomplishment. Simple and little to everyone that has never experienced the devastating impacts of aphasia on a person's life. But for those of you who have seen firsthand what I am talking about, you will understand what a mind-blowing accomplishment this was for us! **And the solution was so simple. If only it had occurred to me sooner!**

If even one other person out there is able to take this information and use it to help a loved one accomplish a similar goal, then my rambling and typing have been **well worth it!**

NAA "Group of the Month"

In keeping with the Multicultural theme - This month we are pleased to feature the Aphasia Group of Thessalonica, Greece. It was started and is facilitated by Hariklia Proios who is a speech-language pathologist and a member of the NAA Multicultural Task Force.

Aphasic Group of Thessaloniki, Greece Hariklia Proios, PhD CCC-SLP

The etymology of aphasia comes from the prefix /a/ which means lack of and the verb "fasko" [which means to speak]. In Greece, Greeks commonly use the term aphasia as a word to refer to someone who is "in his own world." For now, it is a slang word that seems to have the social upper hand in Greece, rather than the more familiar difficulty with expressive (speaking) and receptive (understanding) language which is used in the Western world.



The aphasic support group in Thessalonica was started as a way for people who live with aphasia to find out information, understand the social, psychological and vocational impact that the aphasia may bring. Most importantly the group was established to make everlasting friendships and for all involved. The first meeting was held in the year 2002 at the AHEPA University Hospital by the B' Department of Neurology. The official organization was established in 2004. It has been hosted by various local hospitals and rehabilitation centers including the Revival Rehabilitation Hospital in Nea Redestos.

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NAA "Group of the Month" - continued

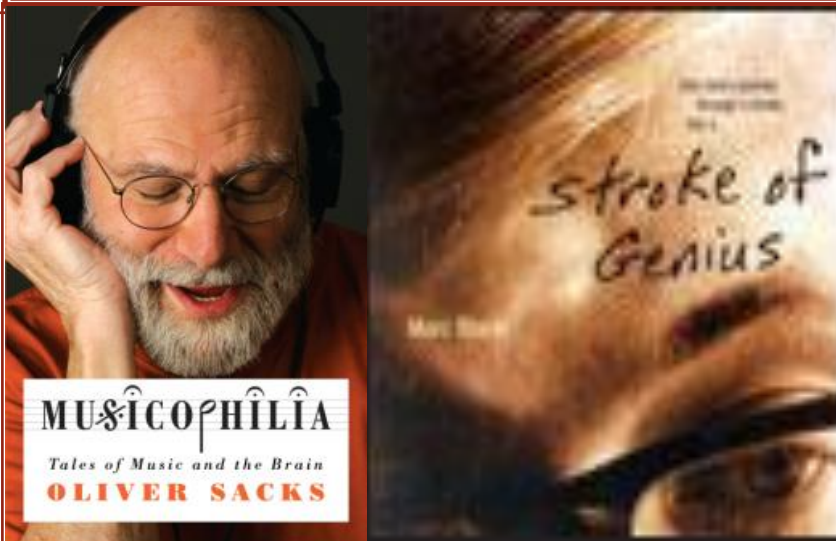
The group has since hosted a number of bimonthly events which includes bouzouki music and dancing (bouzouki is a Greek guitar like instrument), Latin dancing (hosting two professional teachers who were Greek national champions), talks from the actual members about vacation trips (e.g., to a zoo) and more recently in November a well-organized holiday day with singing and craft design (Holiday event for 2007-2008). The pictures below are examples of some of these events. The first picture depicts a movie presentation, the second a bouzouki music event and the third is the ceramic craft activity where a member of our group is being helped by a volunteer.

Our group is supported by many speech-language therapy students, professionals, family members of victims and staff. We are forever grateful for there support. For more information about the group please email Hariklia Proios at hproios@npsy.uzh.ch



Your group can become the NAA "Group of the Month"-There is still availability for August, November and December. Contact Ellayne Ganzfried at Ganzfried@aphasia.org or call (800) 922-4622

There IS Still Time!



The NAA Annual Spring Benefit will be held on Tuesday, April 1st at Comix in NYC. The 2008 Aphasia Advocacy Award will be presented to Dr. Elliot J. Roth.

The benefit will feature a *reading and book signing* by NAA Board member, Dr. Oliver Sacks - world renowned neurologist and au-

thor. Marc Black, singer and songwriter, will *perform songs* with his trio from his acclaimed "Stroke of Genius" CD.

ALL THIS...plus cocktails and dinner, too! You won't want to miss this incredible event.

Contact us at (800) 922-4622 for more details or go to www.aphasia.org.

Become an
NAA
"Group of the
Month"



Each month a different aphasia group will be featured with an article and pictures in our newsletter and in a

highlighted place on our website homepage. It will give you the opportunity to share stories and tell the world what makes your group unique and special. It also helps us keep the connection between

people with aphasia, their families, health professionals and the NAA! Be the first to reserve your spot!

There is still availability for August, November and December. It is a great way to celebrate your accomplishments! If we get enough response then we will feature 2 groups a month!

Contact Ellayne Ganzfried at Ganzfried@aphasia.org or call (800) 922-4622

The NAA's Multicultural Task Force



The NAA's Multicultural Task Force (MTF) has embarked on several initiatives. Information about aphasia has been translated into Spanish, Tamil, Portuguese and Greek and posted on our website. We will soon post information in Russian, Chinese and Hebrew. We have also created a MTF page on the website which includes the mission and goals of the task force, MTF members and a list of state representatives who are multilingual/multicultural. We hope to continue to add to this list and update resources.

Click on this link to view:

http://www.aphasia.org/naa_materials/multicultural_aphasia.html

This month we feature an article from the Task Force.

Understanding Aphasia in Bilingual Speakers

José G. Centeno, Ph.D., CCC-SLP

Associate Professor, St. John's University, Queens, NY

NAA Board Member; Co-Chair Multicultural Task Force



Interpreting language abilities in bilingual speakers with aphasia requires the understanding of multiple variables that may be clustered into three important areas of information: the patient's bilingualism history, the expressive skills typically employed by bilinguals in conversation, and the different language recovery patterns that bilingual speakers with aphasia may exhibit. In this article, I will provide a brief overview of the above three information clusters. Because an exhaustive discussion on the pertinent variables and their interactions is not possible in this short article, some important publications for further reading are given at the end. Though I focus on bilinguals in the discussion, similar principles apply to people that speak more than two languages (multi-lingual's or polyglots).

The Patient's Bilingualism History: Just like monolingual individuals not speaking or writing the same way when they express themselves, all bilinguals are very different linguistically because they exhibit great variability in terms of how they use their two languages and the extent they have mastered each language. Understanding language proficiency and mastery among bilinguals mandates the individual examination of how each bilingual person acquired his/her first (L1) and second language (L2).

Very importantly, equal mastery across all languages modalities (speaking, writing, auditory comprehension, and reading) in both languages is quite rare. The reason is that, for all bilinguals, to be equally competent in both oral and printed forms in each language, they need to experience both languages in the same situations throughout life! What is very common is that one language becomes the dominant one because it is used more frequently across modalities than the other (weaker) language.

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Thus, when putting together the puzzle of each bilingual person's bilingualism history, we essentially need to consider age of acquisition, communication environments throughout life (home, school, work, and social networks), and the language modalities employed in those situations for each language. Age is a crucial factor. Generally, the older we are, the more difficult it is to acquire a second language like a native speaker. Yet, there are certain exceptions, such as talented language learners and highly motivated individuals who immerse themselves in communication environments that allow considerable practice. Further, of all linguistic areas (syntax, vocabulary, morphology, etc.), phonology seems to be the most difficult to master – which explains those cases of very proficient speakers in a second language, who, despite having a great command of vocabulary and syntax, may still have an L1 effect while they speak in L2, often identified as an “accent”.

Expressive Skills in Bilinguals: Having an “L1 accent” when speaking in L2 is not unusual for many bilingual persons. In addition to an accent, some other features may be present when bilinguals converse. Bilingual individuals may use both languages in an utterance or use particular words from one language when not having an exact translation in the other language (language mixing). They may similarly use L1 word order in their L2 utterances (syntactic transfer), exhibit L1 limitations, such as a reliance on simple sentences, due to loss of L1 mastery (attrition), or use expressive features of another community, such as African American English (AAE), in their utterances (dialectal influences) due to frequent exposure. Finally, bilinguals may sound dysfluent, just like a stutterer, as they struggle to speak in their weaker language.

Language Recovery Patterns in Bilingual Speakers with Aphasia: Two main recovery patterns and deficits occur in bilingual speakers with aphasia; parallel or non-parallel. Parallel recovery and impairments, the most frequently encountered profile, involves the simultaneous recovery of both languages and the presence of the same deficits in each language. In contrast, non-parallel recovery and deficits, which may be manifested in various ways, refer to an unequal order in the restitution of the languages or differences in their use. For example, one language is recovered much better than the other (regardless of pre-stroke mastery), one language may be recovered while the other is not, or both languages may be recovered yet used in mixed utterances involving both languages.

So, how do we distinguish in the bilingual person with aphasia those language abilities resulting from bilingualism from those language impairments caused by the stroke? Accurate diagnostic language interpretation in the bilingual person with aphasia would necessitate the evaluation of each language using both formal tests, employing equivalent versions in each language, and informal conversational procedures. Next, analysis of those results should be based on knowledge of the bilingual speaker's bilingualism background as well as knowledge of the typical expressive features used by bilinguals and the possible language profiles in bilingual persons with aphasia.

Suggested Readings :

- Centeno, J. G. (2007). Bilingual development and communication: Implications for clinical language studies. In J. G. Centeno, R. T. Anderson, & L. K. Obler (Eds.), *Communication disorders in Spanish speakers: Theoretical, research, and clinical aspects* (pp. 46-56). Clevedon, UK: Multilingual Matters.**
- Gitterman, M., & Datta, H. (2007). Neurolinguistic aspects of bilingualism. In J. G. Centeno, R. T. Anderson, & L. K. Obler (Eds.), *Communication disorders in Spanish speakers: Theoretical, research, and clinical aspects* (pp. 57-66). Clevedon, UK: Multilingual Matters.**
- Paradis, M. (2004). *A neurolinguistic theory of bilingualism*. Amsterdam: John Benjamins.**
- Roberts, P. M. (2001). Aphasia assessment and treatment for bilingual and culturally diverse clients. In R. Chapey (Ed.), *Language intervention strategies in adult aphasia (4th ed., pp. 208-234)*. Baltimore, MD: Williams and Wilkins.**



We want to feature information about

ALL Aphasia Groups, Centers, events and personal experiences

so please email us at naa@aphasia.org with your announcement or an article of interest about your program.

You can also visit our website www.aphasia.org for all current listings.

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NEWS AND NOTES

⇒ **Speaking Out 2008 Registration forms** are now available on line. Limited affordable lodging available for attendees through NYU dormitory-Housing information is on-line as well or call NYU at (212) 992-9380 or the NAA at (800) 922-4622

Can't attend?

Why not sponsor a person with aphasia or a family member to attend the conference. Sponsorship opportunities are available on the website.

⇒ **Thanks to all that have visited GoodSearch.com** – we encourage everyone to please support the NAA by using GoodSearch as your search engine and selecting The National Aphasia Association as your charity.



What if **the NAA** earned a penny every time you searched the Internet and a percentage of your sale every time you shopped online? Well, now we can!

Just go to www.goodsearch.com and be sure to enter **National Aphasia Association** as the charity you want to support.

Do all your shopping through GoodShop and the NAA gets a gift too!

⇒ **NAA welcomes the following new State Representatives:**

Melinda Corwin-TX,
 Anita Marie Greer-OH, Eileen Erickson-AZ, Elizabeth Laughlin-VA,
 Marissa Barrera-NY, Jill Moore-OK, Traci Iverson-NV,
 Karen Mackenzie-Stepner –Ontario, Canada, Kristy Cyr-MO, Michael Simpson-CA

We appreciate your support!

NEWS AND NOTES

⇒ **First research conference on communication disorders** in culturally and linguistically diverse (CLD) populations Albuquerque, June 6-7, sponsored by the Special Interest Division 14 (SID 14) - Communication Sciences and Disorders in Culturally and Linguistically Diverse Populations - of the American Speech-Language-Hearing Association (ASHA).

“State of the Research on CLD Populations:
Establishing Our Foundation and Advancing Our Science.”

For conference information: http://www.asha.org/about/membership-certification/divs/div_14.htm

⇒ **Student Internships Available** in NAA office in NYC. Contact Ellayne Ganzfried at Ganzfried@aphasia.org or (212) 267-2814

⇒ **The NAA was represented** at the Michigan Speech-Language-Hearing Association Convention earlier this month. Thanks to Sandra Glista and Robin Pollens for coordinating this effort and thanks to all who volunteered!



for the NAA at the following conferences:

April 5

Living with Aphasia-Aphasia and the Arts
Edison, NJ

April 10-12

New York State Speech-Language Hearing Association
Saratoga, NY

North Carolina Speech, Hearing and Language Association
Asheville, NC

April 13-16

National VA SLP Conference
Tucson, AZ

April 16-19

West Virginia Speech-Language Hearing Association
Flatwoods, WV

April 17-19

National Black Association for Speech-Language and Hearing
Crystal City, VA

April 19

Mid-Tenn Conference
Murfreesboro, TN