



**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

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# NEWSLETTER

## MESSAGE FROM THE PRESIDENT OF THE NAA

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In this holiday season, we want to take the opportunity to wish you and your family health, happiness and prosperity. The NAA thanks you for your generosity and support throughout the year and hope that you will, once again, remember the NAA as you make your charitable contributions.

We had an extremely successful experience at the ASHA Convention in November—we handed out thousands of information packets, pens and buttons but most importantly we were visible! The key to increasing awareness is visibility and education. As a result of being at ASHA, we have recruited many new State Representatives, learned of other Community Groups and built new partner relationships. Several of our State Representatives have volunteered to exhibit, on behalf of the NAA, at their individual state conventions throughout the year.

Plans are in full swing for Speaking Out! 2008 which will be held on June 19-21, 2008 at NYU. Also be sure to Save the Date for our Annual Spring Benefit on April 1, 2008. We are thrilled to have Dr. Oliver Sacks speaking and the Marc Black trio performing. Visit our website [www.aphasia.org](http://www.aphasia.org) for additional details.

All the best for a wonderful 2008!

*Barbara C. Martin*



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**The NAA received this email from Melodie Dregansky, NAAState Rep. from Ohio:**

*"Thought you might be interested in this poem. Massel read this at the opening at the conference on aphasia in Toronto. She is a beautiful woman. She is very active at the Aphasia Institute of Toronto."*

**We wanted to share this inspiring poem with all of you!**

**My Aphasia and Me By Massell Smith**

**Aphasia! A time of frightening darkness  
Yet in this darkness, I have found myself,  
Where an interesting new life has open to me  
And inspiration has shown, honest friendship is real**

**Aphasia! You spark determination and humility  
Awake my soul to the wonders of life  
From the glory of the sunset, to the fresh morning dew  
The unique experience of being alive**

**Aphasia! What crowded mind, unscrambled thoughts  
The future looks grim, uncertainty sets in  
But the intelligent mind refuses to cave in  
So the struggles go on day after day  
As courage endure and inner strength shines through**

**Aphasia! Never stop learning as babies do  
Laughter's fill the room  
As funny gestures and sounds act out words in my head  
Elated I stand!**

**Joyful sounds and cheers can be heard all around  
As successfully my challenges are met**

**Aphasia! One message is clear  
Experiences in giving, is pure and a delightful joy  
Receiving is equal and a blessing from above**

**So thanks,  
Is forever spoken by these lips  
It's the love and caring  
Sent from the heart  
And the smiles that shine through  
The receiving heart**

**Aphasia! Humiliation you bring  
My eyes are red, my cheeks are wet  
Angry words burst forth as tears flow  
Why should I be ashamed?  
I never asked for your coming  
Yet you are here to stay  
But my stubborn will, restored self confidence  
Invisible though you are  
Our lives are intertwine as long as I live  
Me and my Aphasia.**

Massell Smith has worked in health services, as both a medical technician and a practical nurse. In November 1999, Massell had a stroke that left her with aphasia. Before her stroke, Massell took pleasure in gardening, theatre and reading. Now she enjoys painting, song writing, theatre, but is most passionate about creative writing with a dream to one day write children's stories. Massell has a strong belief that when something is taken away, something is given in return. This statement is reflective of her positive attitude and outlook on life.

Since 2001, Massell has been attending the Aphasia Institute in Toronto and regularly participates in a number of programs offered at the Pat Arato Aphasia Centre. She often speaks on behalf of the Aphasia Institute. Massell says that she could not have survived and done as well as she has if not for the kind generosity of the staff and friends she has made at the Institute.

Massell chairs the Members' Committee of the Aphasia Institute and is an active member of the Aphasia Institute's Toastmasters International Aphasia Gavel Club, where she has achieved Advanced Toastmaster Gold Level. Massell Smith is proof that life is larger than aphasia

## NAA in Boston!

See photos of our successful ASHA Convention experience on our website

[www.aphasia.org](http://www.aphasia.org)

Thanks to all that visited our booth, volunteered and supported our effort!

### SAVE THE DATE-SPRING BENEFIT!

The NAA Annual Spring Benefit will be held on Tuesday, April 1, 2008 at Comix in NYC. The Benefit will feature a reading and book signing by NAA Board Member, Dr. Oliver Sacks- world renowned neurologist and author. 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. Stay tuned for further details!



#### DID YOU KNOW?

The NAA sends out Free Information Packets to anyone that requests one. It costs the NAA \$4.98 to print and distribute each of these packets so every dollar you contribute goes to our continuing to educate and advocate on behalf of persons with aphasia and their families.

We want to feature information about **ALL Aphasia Groups ,Centers and events** so please email us at [naa@aphasia.org](mailto:naa@aphasia.org) with your announcement or an article of interest about your program.

You can also visit our website [www.aphasia.org](http://www.aphasia.org) for all current listings.

## Brain On Strike-Part 2—By Ethel Lee-Miller

You can read Part 1 in our October Newsletter

*(Continued from our October Newsletter)*

He joined others in aphasia recovery at the Adler Aphasia Center in Maywood, New Jersey. Adler is a haven for aphasia clients and caregivers in offering support groups and daily programs in life experiences—computer skills, reading, writing, art, and cooking, along with constant communication at any and all levels. Paul has learned countless ways to supplement speech to gain understanding. At a party at the Center, part of the entertainment was playing charades. One of the members laughed saying, “That’s what we do all the time.” And it’s true. We all join in gestures, acting, bending, stretching, and pointing to things to speak to each other.

My sister has fourteen folders for the different doctors and countless prescriptions for his meds. I’m astounded at my twin sister’s ability to find, cajole, and convince another doctor, social worker, or administrator to cover more therapy. She developed more routes to hospitals and medi-centers than any metropolitan car service as she put more than 300 miles a week on their car. She persevered through endless paperwork, online research, and phone calls to have Paul qualified for individual private transportation to Adler or to doctor appointments. Where many people might have given up when they compute the comparison of time it takes for the public pickup versus just staying home and watching TV, Paul’s attitude is “never give up.” I feel scared and helpless when Paul throws the paper and pen to the floor and shouts, “F— it, this is too hard, too much!”

Our family rallied to cook, drive, send cards, hug, and support Paul and Eileen and each other. The BMW North Jersey Motorcycle club had a rally that first year to raise money for expenses. His Aero Safety Training Center friends, where he was a flight instructor, invite him to dinners. We’re the lucky ones—we have each other. Many stroke victims do not have such resources we have.

Even though recovery moves forward, it’s like all recovery—two steps forward, one step back. He learned how to say words that start with *L*. But that was the week his blood count was off. He mastered answering the telephone, but he could no longer lift a suitcase with both hands.

*It’s too much. It’s too forever. I hug my husband extra tight each night with a survivor’s guilt. I tell my friends and family I love them more times than they probably think is necessary.*

I’m motivated to take members of my Toastmasters Communications Club to The Adler Aphasia Center to start a speaking class. We go and model eye contact, handshakes, and deliver clear sentences. The aphasia members model courage, humor, and love.

I’m pushed to anger when I’m at a restaurant with an aphasia recovery friend. He tells me the last waitress barked, “Whattsa matter? Cat got your tongue?” as he silently searched his brain to see, hear inside his head, and then say the word *jam*.

I’m moved to tears when another aphasia recovery person asks me in all earnestness, “What do I do when the supermarket clerk says, ‘Get out of line if you’re gonna be so slow about it.’ I was only searching for the word *thank you*,” he tells me with a defeated shake of his head.

All of us in Paul’s world—relatives, friends, neighbors, his former students and colleagues—learn patience, give wait time as Paul searches for a word, no music or TV in the background to reduce distraction, have a pad and pencil handy in just about every room of the house for writing clue words. These are the daily “things” we can do, and I am amazed at the progress Paul continues to make each time I see him.

Most of all, I am in awe of the love I see between my sister and her husband—not only in their obvious affection, but in the quiet way she responds to his frustration, “Paul, listen to me. You have to hold the camera on this side. This way.” He reaches his hands up the way she did, and looks at her with all the trust in the world that this incredible woman will accompany him on the path they are determined to forge together.

This past winter my sister and Paul made the decision to fulfill a long-held retirement dream to move to Arizona. Many friends and family members were less than enthusiastic that they would be moving away from family, friends, and support systems that were built up.

“We’ll find support there,” Eileen stated with incredible confidence. We had vacationed in Arizona and knew there was aphasia work being done at the university. On July 1, 2007, two and a half years after their world turned upside down, Paul and Eileen got in their car, and left New Jersey to drive cross-country for the next adventure. And that’s another story.

## NEWS AND NOTES

⇒ **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. Visit [www.steinhardt.nyu.edu/conference/aphasia2008](http://www.steinhardt.nyu.edu/conference/aphasia2008) for more information

⇒ **NAA is seeking** co-sponsors for Speaking Out! 2010. Go to our website [www.aphasia.org](http://www.aphasia.org) to learn more.

⇒ **Welcome to new NAA Board Members** Dr. Steven Small, Steven Kessler, Esq. and Jose Centeno, Ph.D, CCC-SLP. We are fortunate to have these talented individuals join the Board!

⇒ **Congratulations to Ethel Lee-Miller** on the publication of her book "Thinking of Miller Place: A Memoir of Summer Comfort." Ethel is the author of the article, "Brain on Strike" which was featured in our November and December newsletters