



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

June/July 2008

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MESSAGE FROM THE PRESIDENT OF THE NAA



Summer has arrived! The past month has been filled with many events and lots of excitement! June was Aphasia Awareness Month and there were activities across the country and around the world.

We had our sixth national Speaking Out! conference on June 19-21 and it was a memorable experience for all who attended! Many thanks to all who participated and were involved in the planning. Special thanks to our Executive Director, Ellayne Ganzfried for all her hard work and commitment!

The NAA has a unique opportunity to host a Benefit performance of the World Premiere production of the play "Irena's Vow" starring critically acclaimed actress, Tovah Feldshuh! You won't want to miss this wonderful evening on September 18th, 2008.

As you relax and enjoy the beach, pool and vacations, the NAA continues to work on your behalf to raise awareness of aphasia and advocate for people with aphasia and their families. We need your support and thank you for your generosity and efforts!

Best Regards,
Barbara C. Martin

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We Got Mail!

Here is an email we received from the wife of a man with aphasia in Maryland:

Dear Ms. Ganzfried,

My husband Lee suffered a stroke on Valentine's Day 2006 at 53 years of age, two weeks after cancer surgery. His early prognosis was not good. In addition to leaving him (temporarily) paralyzed on his right side, he lost the ability to speak. He was heartbroken when he could not say our only child's name.

After six weeks in the regular hospital and in rehabilitation [entering in a wheelchair], Lee walked out on his own. Physically, he recovered well excluding lingering numbness on his right side. His aphasia, however, made him unable to hold a normal conversation with family, friends, and co-workers. He spent the next three months going to out patient therapy; speech, occupational, and physical.

Thanks to great speech pathologists and a lot of hard work, Lee was able to return to work two days a week in July, full time in September. His co-workers and his bosses were fantastic, accepting and dealing with his ongoing aphasia. They were not above poking fun at him; but, they also did not baby him. Again, this made all the difference in my husband's recovery.

We have since met other individuals who have aphasia, and in far too many cases, it is my opinion that the insurance companies are far too quick to stop the speech therapy. In my husband's case, he still had trouble holding anything that could be called a normal conversation, could not write well enough to compose emails, and also had trouble reading [comprehension was estimated at around 30 percent]. However, based on the guidelines set by our insurance company, he was considered 'as good as he was going to get.' Therapy came to a halt long before Lee was able to say more than a few words or a short sentence.

Needless to say, Lee was frustrated and afraid that he would never be able to return to work. Based on all the information I could find on the web and in books (including your site), I developed a program to continue to speech therapy at home, starting with going back to the basics. I would, for example, write the word "at" and then write all the various words that could be made with that word (simple phonics). I also used flash cards typically used for children learning how their alphabet, numbers, and how to read.

We met a man in October who was a high school teacher; he also had a stroke following surgery. Because he could no longer speak, he was unable to return to teaching. It is my belief that one of the large differences between this gentleman's recovery -- was that my husband was able to return to work. My husband had no choice but to use his voice, even when the words refused to come out, or came out wrong.

While my husband still has issues with aphasia, it is amazing how far he has come. He is able to do his job, and I would say that about fifty to sixty percent of the time, someone who did not know Lee (before the aphasia) would have no idea that he still battled this horrible disease every day. Having said this, his aphasia is now more a frustration than a hindrance, as Lee is often able to find a different word or he will keep trying to say the word in his head until it 'comes out.'

I welcome your newsletter each month, thrilled to hear about government officials and others who recognize aphasia and battle to help those with aphasia. Please keep up the good work.

Wish I could attend the gathering in NY. Wish you and your organization well.

Sincerely, Shirley Brockett—Maryland

We received a follow up a few days later:

Dear Ellayne,

If you don't mind, I want to add a few other thoughts [which you don't have to include, but I would like to say to someone who understands how aphasia impacts not only the patient, but also the family].

My way of coping with Lee's stroke was to write about it in a daily email to a large group of family and friends. The email kept people informed as to Lee's progress. It also had the added benefit of making my life easier as I did not have to constantly call people to give them an update on Lee, or answer the same questions over and over again. There was a lot of humor mixed in with the difficult times after Lee's stroke, which was included in the emails. Before the stroke, our thoughts were on 'was the surgery to remove Lee's cancer successful?' After the stroke, all thoughts of the cancer were temporarily pushed aside. Lee had a much bigger battle to fight in recovery of his physical abilities and his speech.

I consider Lee to be one of the strongest people I know. He could have easily given up after the stroke. He did not. He pushed himself constantly -- still does. I believe that his desire to recover made a huge difference in how far he has come, as did the fact that we approached his recovery efforts as a team. Our team consisted of Lee and I, but also of many others friends and family that provided support. One example is that after Lee came home from the rehabilitation hospital, I asked his brother Steve to call him daily, another form of therapy for Lee's aphasia. The calls went on for months, until I finally told Steve that it was okay if he did not call every single night. There was a lot of emotional pain during his recovery, but also a lot of laughter. Lee's aphasia had him reversing numbers; my age magically went from 47 to 74 as Lee's aphasia often caused him to reverse numbers.

There were times when Lee was frustrated at what he considered the slow rate of his recovery from aphasia. While the first few months saw far less improvement than Lee wanted, the truth is that he was adding at least a word or two to his vocabulary on an almost daily basis. The, there would be stretches of time when the recovery seemed to slow almost to a stop. A week or a month later, I would suddenly realize that Lee was talking more and having far less difficulty holding a conversation.

When I told Lee that I had emailed you, he asked that I add one more piece of information. That is, that time is a factor in the recovery process of individuals with aphasia. Almost two and a half years after being struck with aphasia, Lee continues to improve.

NAA Group of the Month

Aphasia Awareness Month Host Group Blake Medical Center Stroke Support Group- Bradenton, Florida



The Blake Medical Center Stroke Support Group started in 2000. They are made up of 30-40 participants depending on the time of the year. They meet once per month for a social event and then also have an educational speaker during the meeting. They are made up of nearly half caregivers and half survivors. Age of the group varies from early 40's to in their 80's. Tamara Spyker is the speech pathologist who coordinates the group.

This group developed the theme "Time to Communicate" and helped design the poster that was used to mark June as National Aphasia Awareness Month.

They hosted several events during the month including:

- A Stroke Seminar for the public to increase awareness of aphasia and stroke which included education by physicians, occupational, physical and speech therapists, free blood work for risk factors and information on the Stroke Support Group and Peer Visitor Program
- Held a raffle for community donated gift cards with all donations being given to the NAA. Information on the raffle and donation was submitted to the local paper.
- Provided a survey to Stroke Support Group members to increase awareness of the program and to get feedback for future activities and speakers.

The NAA thanks Tami Spyker and the Blake Medical center Stroke Support Group for their participation and generosity!



National Aphasia Awareness Month!

National Aphasia Awareness Month!

Celebrated Around The Country and in Canada!

Click the link below to read about aphasia awareness events
and see photos!



Aphasia Awareness Month Proclamations were signed in:

- New Hampshire
- New Jersey
- Rhode Island
- Tennessee

Let's go for all 50 states next year!

SPEAKING OUT!

2008

A BIG SUCCESS!



**Conference Co-chairs
Sharon Antonucci and Ellayne Ganzfried**

Speaking Out! 2008 was held on June 19-21 at New York University. The conference was hosted by the Steinhardt School of Culture, Education and Human Development. Special thanks to Dr. Sharon Antonucci, Assistant Professor in the NYU Department of Speech-Language Pathology and Audiology for her dedication and tireless efforts as conference co-chair—This event would not have been possible without her!



**NAA Board Member, Paul Rao,
presenting an advocacy and legislative update**

Over 200 aphasia survivors, co-survivors, students and professionals attended and networked. There were stimulating, informative and heart warming presentations, exhibits and discussions. We had an amazing exhibition of artwork done by people with aphasia. Those that attended the banquet were treated to a wonderful performance of an original song about aphasia called “Tip of My Tongue” along with a group sing-along! We enjoyed spectacular weather as an added bonus!

It takes many people, talents and lots of efforts to have a successful conference and the NAA wishes to thank all of those involved including the speakers, exhibitors, volunteers and attendees!

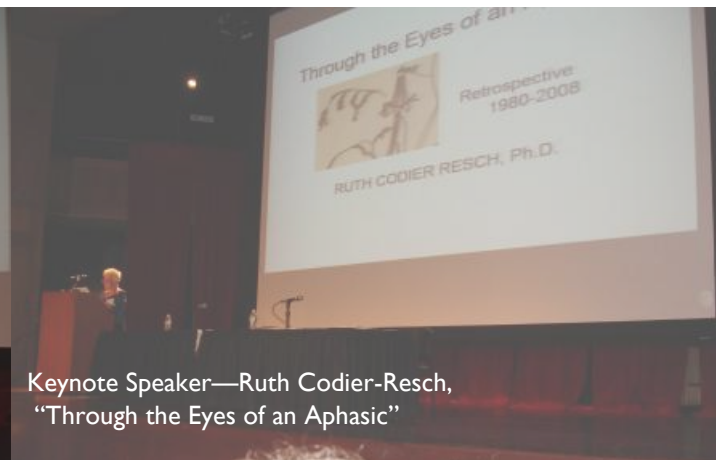
Stay tuned for details about Future Conferences!

Missed the Conference?

A limited number of conference programs are available for purchase at \$10 each. Contact the NAA at (800)



**Keynote Speaker—John Liechty,
“Person Living Well with Aphasia”**



**Keynote Speaker—Ruth Codier-Resch,
“Through the Eyes of an Aphasic”**

A BIG SUCCESS!



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Join the NAA for a Benefit Performance of a new play **“IRENA’S VOW”** starring four time Tony nominee and acclaimed actress, **Tovah Feldshuh!**

September 2008

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

This World Premiere stage production is the true life account of Irena Gut Opdyke’s heroism during World War II. Irena, a 19 year old Polish Catholic girl, was separated from her family during the Nazi occupation of Poland and forced into service as head housekeeper to high ranking Nazi officer Major Rugemer. Unbeknownst to Rugemer, Irena hid twelve Jewish refugees in the basement of the major’s villa for an astonishing two years. This brief synopsis cannot encapsulate the twists & turns, constant dangers and obstacles Irena and her friends encountered in order to keep their secret safe. In the end, every one of the refugees taken in by Irena survived including, miraculously, an infant born in the basement to one of the hiding Jewish couples. One day many years later, this miracle child would find Irena living in America and thank her for the gift of his life.

Irena was later brought to Israel to be honored for her courage and ingenuity. Today, the plaque honoring her bravery stands as a testament to her selflessness and heroism. In 1982, she was named by the Israeli Holocaust Commission as one of the Righteous Among the Nations and was presented with the Israeli Medal of Honor, an honor bestowed upon non-Jewish people who risked their lives in defense of Jews during the Holocaust. The Vatican has given her a special commendation, and her story remains a part of the permanent exhibit at the United States Holocaust Memorial Museum in Washington, D.C.

Irena Opdyke’s mission in the later years of her life was to communicate her experiences first hand to a younger generation. She knew they would be the last generation who would be able to hear a first-person eyewitness account of the horrors of the Holocaust, and she takes her place in history along with heroines such as Irena Sendler.

The Directors Company, Power Productions New York, and The Polish Cultural Institute have now joined forces to bring you the Invictus Theater Company’s production of Irena’s Vow.

Join the NAA on September 18 for a unique opportunity! We will be treated to a special performance of “IRENA’S VOW” followed by a post-show reception where you can meet Tovah Feldshuh, the playwright, Dan Gordon, Irena’s daughter and others whose lives were touched by this amazing woman!

WHEN:

Thursday, September 18, 2008 at 8:00 PM

WHERE:

Baruch Performing Arts Center East 25th Street between Lexington and 3rd Avenues, New York

TICKETS:

*\$150 per person for premium seats
\$100 per person for general seating*

Don’t miss this Incredible Event!

Call the NAA at (800) 922-4622 or email us at naa@aphasia.org for more information and to purchase your tickets!

NEWS AND NOTES

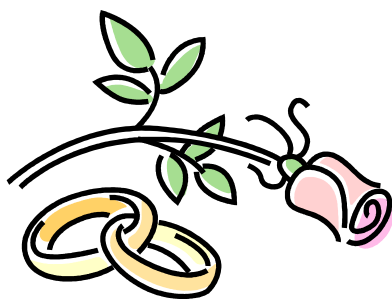
The NAA welcomes the following new
State Representatives:



Michele Poynton-Marsh-DE

Lynn Kostbar-NJ

Katie Holterman-NJ



Congratulations to NAA Board Member,
Josh Roth and Caren Dranoff
on their marriage on July 3rd - Best wishes!

Looking for Pen Pals - Students in the University of Tulsa Aphasia Class are looking for persons with aphasia (PWA) to be their pen pals for the semester. This is a wonderful way to share your experience as a PWA with future professionals, meet new people and use your language in a fun way! If you are interested - please contact: Ellayne Ganzfried at Ganzfried@aphasia.org



NEWS AND NOTES



In partnership with National Aphasia Association, San Diego-based Mo`olelo Performing Arts Company presents *Night Sky*, Susan Yankowitz's moving play about a brilliant astronomer who is rendered aphasic following a car accident.

August 27 – September 21, 2008

Mo`olelo *in Residence* at La Jolla Playhouse, 2910 La Jolla Village Drive, La Jolla, CA 92037

Information & Tickets: www.moolelo.net, 619-342-7395

NAA Ticket Discount: Order tickets online at www.moolelo.net and input the following coupon code to receive \$5 off: GTU58984

Have you scheduled your  interview yet?

The booth is currently available in Manhattan and Nashville but there are mobile booths traveling across the country.

Next stops are:

July 17-August 5 Denver, Colorado

Buffalo, NY

August 28- September 20 Northern Minnesota

Amherst, MA

To learn more contact Ellayne Ganzfried at Ganzfried@aphasia.org



We want to feature information about

ALL Aphasia Groups, Centers, events and personal experiences!

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.