



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

August 2008

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MESSAGE FROM THE PRESIDENT OF THE NAA



Message From The President of the NAA

Hope you are all having a wonderful summer and finding time to relax! At the NAA we continue to advocate on behalf of people with aphasia and their families whatever the season.

Plan on joining us on **September 18th** for a Benefit Performance of the World Premiere Production of the play "**Irena's Vow**" starring the **Tony award winning actress, Tovah Feldshuh!** You will have the opportunity to see an outstanding performance, meet Tovah Feldshuh and support the NAA-You won't want to miss it!

I encourage you to share your experiences with the NAA and provide us with feedback. We want to hear what is going on with aphasia groups and programs around the country. The NAA serves as the central clearinghouse of information and can help connect all those with aphasia.

As always, we appreciate your support and generosity-we could not achieve our goals without it!

Be well and enjoy the sunshine!

Best Regards,
Barbara C. Martin

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We Got Mail!

IT IS ALWAYS NICE TO GET POSITIVE FEEDBACK:

I so want to let you know how much I appreciate you!

You have been to me a measure of help I really could not have fathomed. I would so like to be able to show my appreciation in an appropriate way. I really do not know how to express appropriately, how much

The NAA has helped me, done for me, contributed to my quality of life. If I searched, I don't know that I could find words; to express just how much you have meant to me. You have been to me an ANCHOR in a very turbulent storm....And I so want to thank you for all you have done for myself and others. I would like to say "that your work is rewarding". I pray that God will bless you greatly for all you have provided for people like myself. I had no family, no support, no assistance with my illness --only you....I wish I could find the appropriate words ----and the right way to express my gratitude to you.

**Catherine Cast
Killeen, Texas**

(continued page 3)

Here's a moving personal account by a co-survivor from New York:

Aphasia:

Embracing Lost and Journeying Beyond the Pain to Restoration

It was a beautiful day of brilliance. The sun sat perfectly in the horizon with beautiful rich hues of blues and white splashed across the sky. It's as through it was orchestrated for the baseball game taking place, full of much excitement. Bob and I were rapid walking. He looked at me and asked. "Helene what is your purpose in life?" I thought it to be a peculiar question on in the context of a recreational walk. I responded. " He retorted how do you hope to achieve that? I thought the conversation was too esoteric. He began to walk ahead not speaking. "Bob why are you going over there? Do you know someone there?" The entire right side of his body began to droop. He attempted to stand but his right side would not cooperate. He tried to speak but it was incomprehensible. Half of his face wore a frown.

I knew what was happening because I am a registered nurse. I yelled, "activate EMS, does anyone have aspirin?" I began to pray fervently. Placed in a whirlwind, I tried hard to stay anchored. It seems surrealistic. I talked to my Creator. I thought of no one else. Our faith in God had always been our strong foundation throughout our marriage. I observed Bob's eyes watching my every movement. I eventually realized my nervousness was channeled into business. I desired to do all I could to save my husband's life. My business was also allowing me to not explode as I saw my preexisting life slipping away.

Bob and I reunited in the Emergency Room at a local hospital. It was there I was forced to make decisions quickly. Do we pursue an experimental procedure and chase blot clots? There was no neuro ICU available so I elected to transfer my husband to another hospital. The lesson learned over the years, are for stroke designated centers to be the port of call for stroke victims. He was transferred and placed in a neuro intensive care unit.

I find myself being present in body but not mind. Most of my immediate family was present doing their best to encourage and extend their remorse over our tragedy. Their support quickly dissipated. They did not realize the assault a massive stroke has on the person and their loved one. We are strong and tend to present invincibility. They are at a loss as to how to help. We needed to be taught how to cope. They were forced to see their own mortality. It simply hurts, terribly affecting every fiber of your being. Every facet of your daily existence stops and is altered. The hole is so large, so dark seemingly insurmountable.

I prayed that my heart not stay hardened. I yearned for support. I sought out an objective listener. I chose to go to my church and expose my human fragility to my pastor. I found an Aphasia center and attended three days per week with my husband. This was not an easy task since I worked daily. I began to pull on the resources I used in the past that were effective. I chose to be open and honest with those who were close to me about my emotional and spiritual self. I even made new friends along the way that were sensitive to our needs. I realize old friends and family members found it unbearable seeing this new Bob and Helene. We realized that healing is a process. It takes a community to move to the point of survivor over pain.

Helene Durham

Wesley Hill, NY

NAA Group of the Month

Suncoast Aphasia Support Group Sarasota, Florida

Suncoast Aphasia Support Group has been a reality for over a year now! What started as a seed in the minds of two co-survivors who knew they had to “do something” is now a vibrant first Monday night of the month group with thirty some members. If you asked those members why we are unique and a little different these are some of the things I think they would tell you about.

First of all Erika and I are co-survivors. Our husbands had strokes several years ago , and we have been through the usual rounds of therapies, support groups and doctors. However, we had not found quite the right mix of enthusiastic, social, and informative groups that could carry on month after month in such a way as to keep up our interest. So we thought, why not???????



Our secret is our hearts. We have lived this and our hearts and souls are in it. We try to plan programs which give our friends hope, information , fun and , friendship, Our monthly agendas keep everyone informed as to what will be going on at the next meeting and in the future. Our meetings are structured into 3 parts- a business meeting , the main activity , and the break-out sessions with separate survivor and co-survivor groups. We are always looking for inspiring stories and information to share and try to keep up on all the latest research. We have a place reserved at each meeting for anyone to share this information, We have also recently been asked to participate in a research project for a national study. Each month we try to build in fun activities, either by using word games, or some language activity, and the very most rewarding aspect of the group is the life-long friendships we have all made. We can't imagine life without these people who are the essence of what the group is about.

Our uniqueness—What makes us who we are--**we keep everyone busy** every month. We have social activities each and every month. March was a picnic on Lido Key, April was a barbecue and game night at a condo, and May was a ride on a train for a dinner and an interactive mystery that sounds like a lot of fun. Also after each of our meetings we have reservations at a restaurant, and we have dinner together for socializing and getting to know each other better. This has just developed over the past year. It started with just a couple of people going out for pizza, and has turned into a group outing for dinner the first Monday of every month after the meeting. We have also initiated a project that allows the stroke survivor to speak about his/her life , called “Who Am I “ in a non-threatening environment. We have had some very, very interesting speakers over the past year- from a rehab neurologist to an acupuncturist which also added greatly to our meetings.

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NAA Group of the Month “Continued”

Suncoast Aphasia Support Group-Sarasota, Florida



The Future and Our Dreams –Our immediate future has a book club that we have in the planning stages and a Karaoke night with tunes everyone knows. We can't wait for that. We might even have prizes!!! Who knows what will happen? As for our dreams, we hope that one day we will be able to turn our support group into a community center where people with aphasia can come and take classes to improve skills, learn a new skill. or just socialize with friends. Right now we try every month to be the best support group we can be and be there for the people we serve-those survivors with aphasia.

Erika Boyle boyle1115@comcast.net

Diane Lombard bdlombard@comcast.net

Another NAA Group of the Month

Toledo Area Aphasia Support Group & DaZy Aphasia Centre

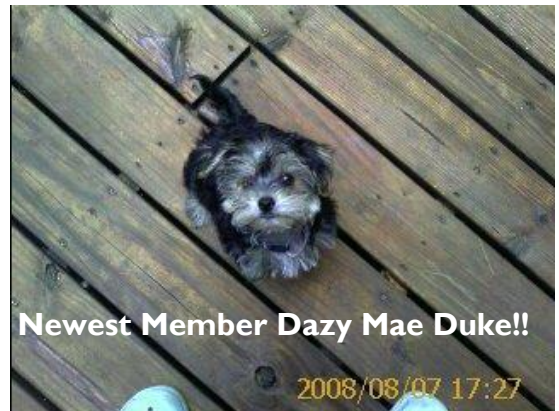
Never would I have thought at 50 I would start a business and begin my life anew. Like so many of our members; I have changed my life goals and am a better person for it. As a favorite book title says.....

"A Stroke of Luck".

After leaving a job working exclusively with people with aphasia, I knew this was the direction I wanted to continue to pursue for my career as a speech therapist, but HOW???? Most inpatient and outpatient speech therapy centers see many different disorders and often are expected to treat children, also. So, I began working part time at a private physical therapy office seeing clients who also needed speech services. I enjoyed this and was able to continue to see a client I had met at my previous job.....long story short:

The two of us and our husbands began what is now called the DaZy Aphasia Centre.

Jackie Zychowicz, a former nurse, and a woman, who at work at the age of 57, had a stroke. She is now a person who is definitely living well with aphasia, but that was not always so. Jackie began her speech therapy with me when she was unable to communicate except at the most basic level and then with her ever present conversation book. She now writes articles for the news papers, does all our brochures and calendars and keeps all of us on track...but that is another story, see her article in last year's September NAA news letter.



Newest Member Dazy Mae Duke!!

The first overnight adventure that Jackie and I attended was a HOPE for Stoke symposium in Cincinnati, Ohio. We

met many professionals, and persons with aphasia and their loved ones. We asked a lot of questions and the advice took to heart was; **the aphasia groups that are most successful are the ones that meet weekly...** that makes sense, due to the nature of aphasia and the time it takes to get to know someone; but what a commitment!!!!

Jackie and I came home and on Sept 19, 2006 we started our support group at the PT office where I was working. We meet every Wednesday night at 5:30 and then go out to eat together at a local restaurant for continued conversation. Needless to say many times it was only the three of us, Jackie, Frank, her husband, and I but we missed only a few meeting dates. One in particular I will always remember was when there was a winter storm and everything was cancelled in our area. Frank called the TV stations and told them that the aphasia support group was cancelled so they scrolled it across our local stations...that's when we got two of our favorite members. Maggie's daughter saw it and the rest is history. Linda, her best friend since high school, brings her and Linda is also our secretary and all around "sunshine" person sending cards and notes to everyone for all occasions. You never know where you will find your members. *(continued on page 7)*

Continued NAA Group of the Month

Toledo Area Aphasia Support Group & DaZy Aphasia Centre



We now meet weekly in the DaZy Aphasia Centre, a 1350sq. ft. space that has programming two days a week for people to come and learn to live well with aphasia. We took a chance and we are so glad we did. Do we have trouble paying the bills sometimes, CERTAINLY!!! But life is too short not to take risks.

Attend an aphasia support group....no group in your area....START ONE!!!! You will be glad you did.

We are located at 2940 Douglas Rd. in Toledo, Ohio 43606.
Email dazyapasiacentre@bex.net

The DaZy APHASIA Centre is open 11-4 Tuesdays and Fridays, and on Wednesday nights 5-6:30 soon, check out our new website with all our information dazyaphasiacentre.org

**Toledo Ohio and the DaZy Aphasia Centre are hosting the
2009 MID WEST APHASIA CONFERENCE.**

LOOK FOR MORE INFORMATION SOON AND SAVE THE DATE: OCTOBER 16-18, 2009

QUOTES FROM MEMBERS:



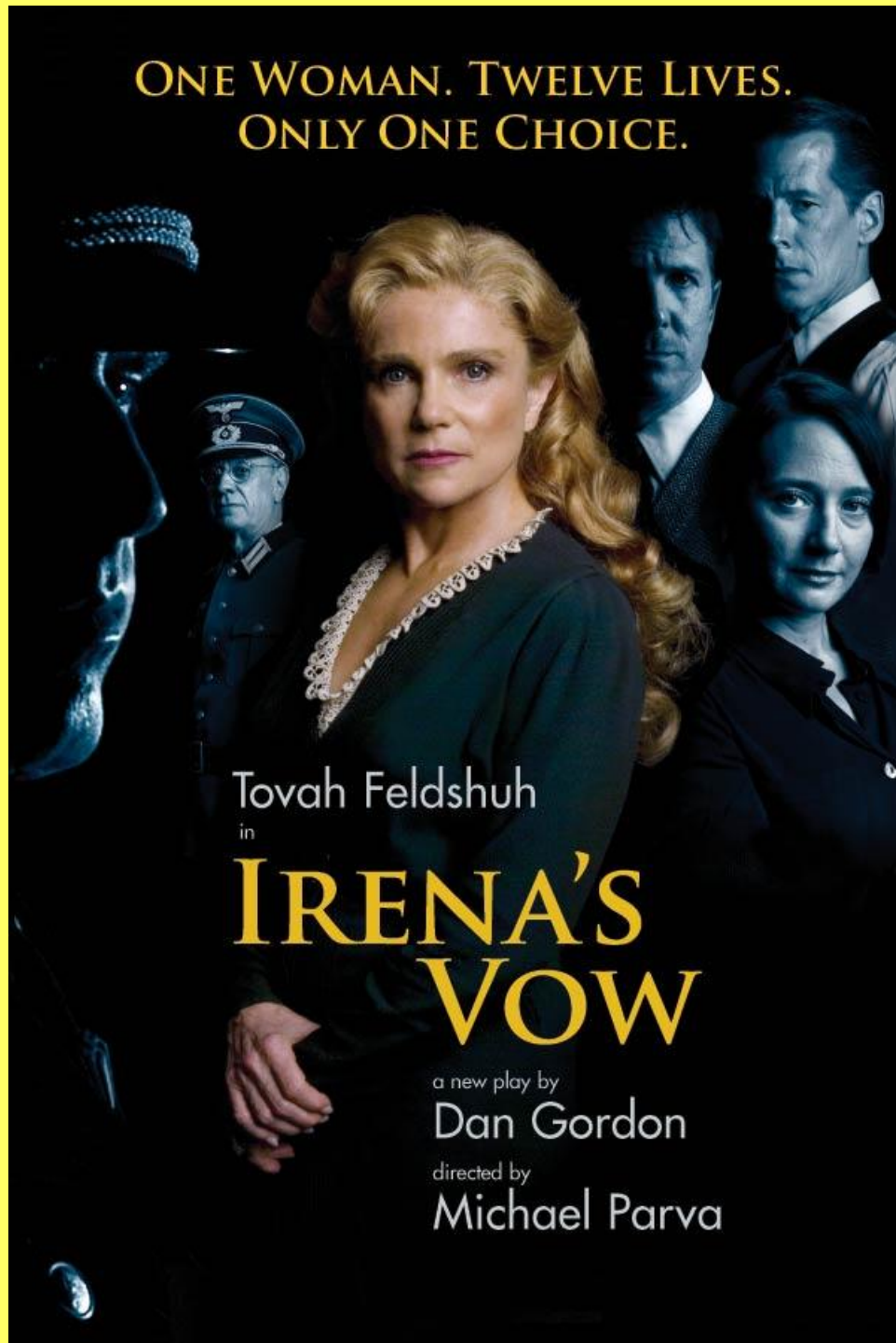
“The DaZy Aphasia Centre was a life saver for us! Support, friendship and time with other aphasia survivors has been wonderful for us” Ken, 49 years old, 1 year post stroke and his wife Judy Robbins.

I am a caregiver. Maggie and I have been coming to the support group for over a year. I have seen improvement in all the people who have aphasia in the group. Keep up the good work. “ Maggie 7 years post stroke and Linda, her best friend.

SAVE THE DATE - SEPTEMBER 18th, 2008

NAA Benefit Performance of "Irena's Vow"

starring four-time Tony nominee and acclaimed actress, Tovah Feldshuh!



NAA Benefit Performance of "Irena's Vow"

starring four-time Tony nominee and acclaimed actress, Tovah Feldshuh!

**Join the NAA on September 18th
for a unique opportunity!**

We will be treated to a special performance of this *World Premiere* stage production of "Irena's Vow," followed by a *post-show reception where you can meet Tovah Feldshuh* and others whose lives were touched by this remarkable woman!

WHEN

Thursday, September, 18th, 2008

WHERE

*Baruch Performing Arts Center
55 Lexington Ave
(Entrance at 25th St btwn Lexington & 3rd Avenues)
New York, NY*

Subway: R, W, 6, 1 to 23rd Street

Bus: M1, M2, M3, M5, M6, M7, M15, M18, M101, M102 to 23rd Street.

Parking: 24th Street (One garage btwn Lexington & 3rd, three btwn 2nd & 3rd Avenues)

TICKETS

\$100 per person (General Seating)

\$150 per person (Premium Seating)

65-75% of all ticket sales to benefit the NAA!

Click here to download your RSVP form!

MORE INFORMATION

Call (800) 922-4622 or email us at naa@aphasia.org

DON'T MISS THIS INCREDIBLE EVENT!!



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



The **NAA** welcomes the following new
State Representative:
Ken O'Brien - NJ

*The NAA thanks **The Laura B. Vogler Foundation** for their generous grant towards “Aphasia Awareness Training for Emergency Service Providers” Project*



Have you scheduled your StoryCorps 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 23 _____ Denver, Colorado

_____ Buffalo, NY

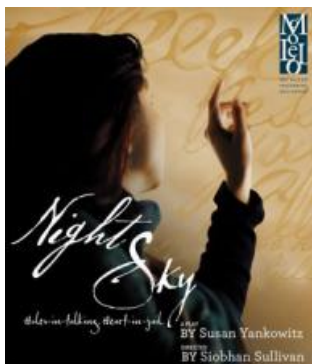
August 28- September 20 _____ Northern Minnesota

_____ Amherst, MA

You can also schedule a “DOOR TO DOOR”- If you have a support group in the NY Metropolitan Area you can have StoryCorps come to you!

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

NEWS AND NOTES



August 27 – September 21, 2008

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.



The NAA sadly notes the death of **Gene-Gabriel Moore** on July 26, 2008 in Atlanta. After a career as a journalist and public television interviewer, Gene-Gabriel Moore suffered a series of strokes and surgeries that affected his speech and left him physically disfigured. But he was not about to be defeated by bad health. While in his early 60s, the aphasia victim founded Not Merely Players, an acting ensemble for the disabled, and reinvented himself as a chipper elder spokesman of the Atlanta theater community. In 2005, he founded the Suzi Bass Awards, the city's only professional theater honors. At age 71, he staged an 11th hour theatrical comeback performing "Struck Dumb" in Atlanta and Boston—a monologue about a person with aphasia written by Jean Claude van Itallie and Joseph Chaiken. The NAA worked with Mr. Moore to publicize this inspiring play. A celebration of his life will be held on August 25th at 7 stages in Atlanta which was his theater home.

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 follow coupon code to receive \$5 off: **GTU58984**
Stay tuned for news about a NY performance of Night Sky!



Visit our Website

www.aphasia.org