



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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Best wishes for a Happy and Healthy New Year! Thank you for your generous support of the NAA-we could not continue our valuable work without it.

We are very excited about this year's Spring Benefit which will be held on April 1, 2008 at Comix in NYC. It is an honor to present our 2008 Aphasia Advocacy Award to Dr. Elliot J. Roth who is the Sr. Vice President and Chief Academic Officer at the Rehabilitation Institute of Chicago (RIC). Dr. Roth and RIC have been instrumental in increasing awareness of aphasia through their many projects and have provided stability to the NAA as we pursue our goals. You will also have the privilege of hearing Dr. Oliver Sacks speak and the Marc Black Trio perform. I had the opportunity to attend a performance by Marc Black of selections from his "Stroke of Genius" CD and found it extremely touching, inspiring as well as entertaining.

The NAA is always looking to expand our network of State Representatives and Aphasia Community Groups so please contact us if you would like to be listed. Be sure to continually visit our website www.aphasia.org for new resources and information about upcoming events.

2008 looks to be a busy and dynamic year- In addition to the Benefit we are looking forward to Speaking Out 2008 in June. The Board has recently met and updated our strategic plan so we are energized to move ahead. We are forming several committees in order to get the job done so if you are

interested in becoming more involved with the activities of the NAA please contact us at naa@aphasia.org or (800) 922-4622



Best Regards,
Barbara C. Martin

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We are pleased to print this article written by Marjorie L. Faes which talks about her "experience as caregiver for her father who has aphasia. She had a similar article published in Stroke Connection Magazine this past year.

Ms Faes wrote: "I am very glad that your organization exists. It is wonderful that you are trying to spread the word about what aphasia is to the general public. Till it hit us close to home, we had no idea what it was all about.

Thank you for the work that you do"

Lessons We Have Learned

BY: Marjorie L. Faes, Caregiver

East Amherst, New York

My family is lucky and we know it. In 2003, my father had a massive brain aneurysm and stroke. The severity of his stroke made it impossible to predict what the outcome would be. At the time things looked grim. Back then we never dreamed that he would make an almost complete physical recovery. Now, at 83, he works out daily and takes long walks. The only daily supplement he takes is a multivitamin. We are lucky because the only major result of my father's stroke is his aphasia.



Before this happened, we, like most of the population, had no idea what aphasia meant. None of us had ever dealt with it before. In the last four years we have been privileged to be Dad's caregivers as he continues to battle his aphasia.

Here are some of the lessons we have learned:

- (1) **You can learn valuable day-to-day coping skills as a caregiver from nurses, physical therapists, support groups, and from articles on the Internet.**
- (2) **Use only tools that work for you. My father wouldn't carry a writing pad, draw pictures or use a special computer. We simply listen to the context of what he is saying and guess at appropriate words. This works 95% of the time.**

(Continued on page 3)

Charity of the Day

For the past year we have been telling you about GoodSearch.com and how the NAA can benefit. We are pleased to announce that the NAA has been selected as the by [GoodSearch](http://GoodSearch.com) for January 24, 2008. Our website and logo will be featured on the [GoodSearch](http://GoodSearch.com) homepage the entire day. Please support the NAA by using [GoodSearch](http://GoodSearch.com) as your search engine and selecting The National Aphasia Association as your charity. It is a simple way to provide a lot of support! Help spread the word by forwarding this message to all your friends and family!

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!

GoodSearch.com is a new search engine that donates half its search revenue (about a penny a search) to the charities its users designate. You use it just as you would any search engine, and it's powered by Yahoo!, so you get great results. It adds up - just 500 of us searching four times a day will raise about \$7300 in a year without anyone spending a dime! In addition, more than 100 retailers including Target, Macy's, The Gap, Best Buy, Nordstrom, [PetSmart](http://PetSmart.com), Staples and [Wal*Mart](http://WalMart.com) have teamed up with [GoodSearch](http://GoodSearch.com) to donate a percentage of each sale to the nonprofit or school of your choice!

Just go to www.goodsearch.com and be sure to enter [National Aphasia Association](http://NationalAphasiaAssociation.org) as the charity you want to support. And, be sure to check out GoodSearch on **January 24, 2008** as we are going to be featured as the Charity of the Day!

(Lessons We Have Learned continued from page 2)

- (4) Patience isn't always a virtue with aphasia. After three or four guesses at a word we stop and move on. At a certain point, it only makes sense to end every one's frustration at finding a specific word.**
- (5) Have a quick and easy description of what aphasia is when people ask. We say that he has trouble finding the right words and cannot read or write.**
- (6) It is hard for outsiders to understand the effects of aphasia if the survivor looks physically fit.**
- (7) My father loves my dog, Morgan, almost as much as I do. He offers to walk, feed and play with her. Pet therapy isn't just for people in nursing homes. The benefits that stroke survivors and those with aphasia receive from taking care of an animal greatly helps in their recovery.**

Extended Day Aphasia Program at the Ladge Speech and Hearing Center at Long Island University, C.W. Post

For the person with aphasia, communication barriers presented by language impairment may be the most challenging than impairment resulting from stroke. In order to address the communication needs of individuals with aphasia, aphasia remediation has a dual focus: first, to develop functional communication techniques that will maximize the successful exchange of ideas; second, to minimize, as far as possible, the degree to which aphasia affects the person's ability to participate in activities he/she enjoys.

To promote this model of aphasia rehabilitation, the American Speech-Language Hearing Association has established a *Life Participation Approach to Aphasia (LPAA) Project Group*. *This therapeutic model specifically targets environmental factors that the aphasic person encounters identifying communication barriers, training spouses, children, friends and others to become communication partners thus creating a more "aphasia friendly" accessible and satisfying life. The goal is to establish and maintain social links that decrease isolation for the person with aphasia and ultimately to reduce dependency on a single caregiver. (<http://www.asha.org/public/speech/disorders/lpaa.htm>)*

University clinics, like the Ladge Speech and Hearing Center, are often the places where long-term, low cost therapeutic services can be provided. We are expanding the individual and group speech-language therapy we currently provide people with aphasia through the establishment of an extended day program. This program is a place where people with aphasia and their families can engage in a variety of social and therapeutic activities with the aim of decreasing isolation, aiding adjustment to disability, improving self esteem and reducing dependency on a single caregiver. Most of these activities are conducted by graduate student interns in speech-language pathology under the supervision of NYS licensed speech-language pathologists.

**This program serves people with aphasia whose comprehension is good enough to follow a conversation and sustain four hours of interaction.
Healthcare aids or other caregivers are welcome.**

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Extended Day Aphasia Program—continued

PROGRAM SCHEDULE:

- 10-11 Meet and greet : general conversation
- 11-12 Focused communication groups with at least two choices
 - Ex: Communication for daily living
 - Current events
 - This week in sports
- 12-1 LUNCH
- 1-2 Social activities: non-linguistic, educational and social activities (art, music, exercise, dance, cards, etc.).

The power of the socialization component of this program is palpable. As the clients come to know each other, they grow more secure and willing to communicate with each other and the staff. During the meet and greet sessions in the morning, a conversational din fills the room. Some days more structured topical group activities are delayed so as not interrupt the on-going conversations.

Clients who were first passive and somewhat inattentive, have become animated. Their personalities becoming more apparent as they connect with others and participate in enjoyable activities of their choosing. The following are statements for people with aphasia and their spouses who participated in the six week program piloted last summer. One spouse said of her husband with aphasia, "I really didn't think I would see much change in just six weeks, but he's so much more like his "old" self. His is expressing more spontaneously. He is making jokes and commenting to strangers which he never did." One of the clients with aphasia said, "This program is 110%! I learned computers. I really, really, appreciate it." A third spouse reported, "Even our friends have commented that Tom is talking more. He is saying three and four syllable words more clearly and attempting longer words that he wouldn't have even tried before." Another client likes the program because, "I am always busy." We strive to make this program a place where the affects of the aphasia are minimized. A place where people with aphasia can effectively communicate with others. A place where people with aphasia can make new friends.

The program meets one Mondays from 10 AM to 2PM from February 4 through April 21st, 2008. The summer program will meet on Mondays and Wednesdays from 10AM to 2PM for six weeks in July and August. For more information contact Dr. Dianne Slavin at dclavin@liu.edu or Dr. Joyce Rubenstein at jrubenst@liu.edu or call 516-299-2437.

WE NEED A HOST GROUP

June is National Aphasia Awareness Month and each year the NAA asks for an Aphasia Community Support Group to serve as the Host Group. The group is responsible for working with the NAA to determine a theme for the month and design a poster and related activities. The host group is featured on the poster and in all press related to National Aphasia Awareness Month. It is a unique and exciting opportunity to help spread the word about aphasia!

**If your group is interested please contact
Ellayne Ganzfried at Ganzfried@aphasia.org or
(800) 922-4622 by February 15th.**

SAVE THE DATE-SPRING BENEFIT!

The NAA Annual Spring Benefit will be held on Tuesday, April 1, 2008 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 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. Look for your invitation in the mail. Contact us at (800) 922-4622 for more details.

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.

It is with great sadness that we report the death of

THOMAS ANDERSON, M.D.,

We extend our heartfelt condolences to his wife, Carol, and his family.

DR. THOMAS ANDERSON, ONE OF THE FOUNDING MEMBERS OF THE NAA AND A LONG TIME BOARD MEMBER OF THE ORGANIZATION, DIED ON SEPTEMBER 8, 2007, AFTER A LONG BATTLE WITH PARKINSON'S DISEASE. THROUGHOUT HIS ILLNESS HE MAINTAINED A ZEST FOR LIVING, LOVING HIS FAMILY, AND WITH FOND MEMORIES OF FRIENDS AND COLLEAGUES IN THE REHABILITATION FIELD, ESPECIALLY THOSE ASSOCIATED WITH THE NAA. HE IS SURVIVED BY HIS WIFE, CAROL, TWO DAUGHTERS AND A SON.

DR. ANDERSON'S PROFESSIONAL CAREER CENTERED ON THE GROWTH AND DEVELOPMENT OF MEDICAL PROGRAMS THAT MET THE NEEDS OF PERSONS WITH DISABILITIES, ESPECIALLY THOSE WHO HAD SUSTAINED A STROKE OR HEAD INJURY. HE LEAD THOSE PROGRAMS AS PROFESSOR OF REHABILITATION AT THE UNIVERSITY OF MINNESOTA, AT THE SPAULDING REHABILITATION CENTER IN BOSTON, AND WITHIN THE NEW MEDICO PROGRAMS NATIONALLY IN THE 1980s HE WAS A PRESIDENT OF THE AMERICAN CONGRESS OF REHABILITATION AND LEAD ONE OF THE FIRST REHABILITATION GROUPS TO TOUR CHINA AND CONSULT ON NEEDED REHABILITATION PROGRAMS THERE IN THE MID 80s. AMONG HIS MANY PROFESSIONAL RECOGNITIONS, HE RECEIVED THE GOLD KEY AWARD FROM THE AMERICAN CONGRESS OF REHABILITATION MEDICINE FOR HIS DISTINGUISHED CONTRIBUTIONS TO THE FIELD OF REHABILITATION MEDICINE.

ONE OF HIS FINAL ACTS WAS TO SEE THAT A CHECK WAS SENT TO THE NAA FOR HIS CONTRIBUTION TO THE ORGANIZATION IN 2007. HE CONTINUED TO SUPPORT THE NAA IN HIS THOUGHTS AND ACTIONS AND TO VALUE HIS CONTACTS WITH COLLEAGUES , FRIENDS, AND FAMILIES WITHIN THE NAA THROUGHOUT HIS LIFE. WE EXTEND OUR APPRECIATION FOR HIS WORK ON BEHALF OF THE NAA AND OUR ADMIRATION FOR HIS CONTRIBUTIONS TO THE FIELD OF REHABILITATION TO HIS FAMILY.

NEWS AND NOTES

⇒ **Speaking Out 2008** to be held June 19-21, 2008 at New York University. Visit 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 to learn more.

⇒ **The NAA extends our sincere condolences** to Wanda Webb and her family on the untimely loss of her husband, Joe Luttrell. Wanda has been very active and a strong supporter of the NAA for many years.

⇒ **Welcome to new Advisory Council members** Darlene Williamson and Maura English Silverman. We also welcome new State Representatives: Teresa Brobeck-NM, Janet Whiteside-FL, Carolyn Falconer-NY. We look forward to working with these talented individuals and appreciate their involvement.

⇒ **Many thanks to our dedicated volunteers:** Fran Epstein, Sophia DeMonte, Stephanie DeMonte, Anna Sandoval. We could not get things done without you!

⇒ **If you would like to join the NAA Volunteer Pool** –contact Amy Coble at naa@aphasia.org or call us at (212) 267-2814.