



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

May 2008

350 Seventh Avenue, Suite 902
 New York, NY 10001
www.aphasia.org
 (800) 922-4622
 FAX (212) 267-2812

MESSAGE FROM THE PRESIDENT OF THE NAA



Happy May! We are getting excited about our upcoming Speaking Out! Conference to be held June 19-21 at New York University. There is still time to register because you won't want to miss this terrific event! I invite you to take advantage of the opportunity to sponsor a person with aphasia to attend the conference. Many people have limited resources and would otherwise not be able to attend so consider sponsoring someone to attend Speaking Out! 2008.

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. Check inside to see where they will be next. We are also going to have a special StoryCorps booth at the Speaking Out conference-there is limited availability so reserve your spot now.

June is National Aphasia Awareness Month. We are thrilled to report that the resolution declaring June 2008 National Aphasia Awareness Month unanimously passed the House and Senate on May 14. Special thanks to Senator Tim Johnson, SD, and Congressman Edward J. Markey, MA, for their sponsorship. We encourage you to thank the sponsors and to get your local representatives to proclaim June Aphasia Awareness Month in your city/state. We have sample proclamations on our website. The NAA and Aphasia Awareness Month was mentioned in the May/June issue of StrokeSmart magazine.

As we continue to work towards achieving our mission and goals your support is invaluable. We thank you for your generosity and your efforts. We look forward to hearing from you and increasing awareness of aphasia together!

Best Regards,
Barbara C. Martin

IN THIS ISSUE:

WE GOT MAIL	2
STORYCORPS	4
NAA Group of the Month Rehabilitation Institute of Chicago(RIC)	5
Museum of Modern Art	6
NEWS AND NOTES	9

We got Mail!

WE RECEIVED THIS EMAIL IN RESPONSE TO OUR APRIL NEWSLETTER!!

Mary Beth Clark, an NAA state representative from Wisconsin,
sent us this email

Thanks for sending the newsletter via the NAA site. I was excited to read about StoryCorps. We have actually incorporated the StoryCorps idea into our aphasia group. It's been a wonderful, amazing and enlightening experience for everyone. The StoryCorps idea lends itself to so many rich ideas for conversation. We have archived stories from some of our members and then played them back from time to time.

WE have also explored the stories within the book, *Listening is an Act of Love*. The group members have really enjoyed this curriculum experience. I think it's great that you have worked on getting the StoryCorps mobile to the cities mentioned. I've joked with our group that one day the StoryCorps mobile will pull into our parking lot at Bethesda Lutheran Church here in Eau Claire. Our group just laughs. I look forward to sharing the newsletter with them.

*Here are excerpts from an email
received from the wife of someone
with Primary Progressive Aphasia (PPA)*

Thank you so much!

I am highly impressed with your quick response time.

I have worked in the corporate customer service of a national footwear company for almost 30 years, and couldn't have asked for better service.

My husband was diagnosed with Alzheimers in April of 2005, and age 63.

In the notes I gave to the doctor at the neurology care center in Indianapolis in 2005, the first item I listed under possible diagnoses was "Primary Progressive Aphasia/Alzheimers". Until a week ago, none of his doctors have even mentioned PPA. Last week his doctor said that my notes regarding changes in his condition over the past 6 months was textbook PPA. Reading back over all of my other 6-month updates, they all read very similar. I have to wonder if anyone was reading them.

I did not research PPA any further from April 2005 until last week. I found your website to be VERY informative and helpful. The information says that PPA is a 'rare' form of aphasia. However, I find that difficult to believe. I think that physicians are not very well informed about this disorder. At this point in history when so many of us fall into the "senior" age range, I believe PPA is going to be seen much more often, just by the sheer numbers of older people who are affected with different forms of dementia.

I could go on and on. I am anxious to learn more, and be a good help-mate for my husband, and educate our families. I'm still working full-time, but plan to retire at the end of this year. Perhaps I can arrange to be a volunteer of some sort after I retire.

Again, thanks for your quick response.

Have a great week!

N.A.

Richmond, Indiana

We need you to Join the NAA in an exciting project with StoryCorps



"Since 2003, almost 30,000 everyday people have shared life stories with family and friends in our StoryBooths. Each conversation is recorded on a free CD to share, and is preserved at the Library of Congress. Millions listen to our broadcasts on public radio and the web. StoryCorps is the largest oral history project of its kind."

Everybody's story matters. Every life counts.

The heart of StoryCorps is the conversation between two people who are important to each other. You can talk about anything that matters to you. By helping people to stop, listen and connect with each other, the StoryCorps experience is powerful and sometimes even life changing.

The National Aphasia Association and StoryCorps invite you to come and share your stories. Record a conversation for yourself as individuals, your families, community and for history.

You can call Veronica Ordaz, NYC Community Outreach Senior Coordinator at 646.723.7020 ext 13 or at vordaz@storycorps.net to learn more and schedule an appointment

or contact Ellayne Ganzfried at Ganzfried@aphasia.org

The StoryCorps Booth is located in Manhattan and Nashville with opportunities available in other cities/states through the Mobile Booth Tours.

Upcoming Mobile Booth Dates:

May 15-June 17	Boise, Idaho Cincinnati, Ohio
June 19-July 12	Laramie, Wyoming Glen Falls and Saranac, NY
July 17-August 5	Denver, Colorado Buffalo, NY

**Are you attending
Speaking Out in June?**

Special opportunity to record a StoryCorps conversation on Friday, June 20 at the Speaking Out conference at NYU.

Contact Ellayne Ganzfried at

Ganzfried@aphasia.org to learn more.

To read more about StoryCorps and the new book, "Listening Is An Act of Love," go to www.storycorps.net.

NAA Group of the Month

The Rehabilitation Institute of Chicago (RIC) Aphasia Advocacy Group

The Rehabilitation Institute of Chicago (RIC) – Center for Aphasia Research was established in 2001. We started providing weekly conversation groups in 2002 and added a book club in 2003. Now we have a variety of groups that meet on Tuesdays and Thursdays. Recently, these groups have included a biographical writing class, and conversation groups about art appreciation, current controversies in the news, and wellness.

For this newsletter, we would like to highlight our newest group, our Aphasia Advocacy group. The group began in January 2008 and is ongoing. Since we started, about 10 different people have been involved with our many projects. Our current group consists of 5 people with aphasia, one speech therapist coordinator, and a student intern. We meet weekly for an hour and a half to “Get the Word Out” about Aphasia. For example, our projects have included:

- **Seeking Chicago Mayoral and Illinois State Gubernatorial Proclamations for “June is Aphasia Awareness Month”**
- **Presenting “Living with Aphasia” by Dr. Bob Walsh, professor emeritus and aphasia survivor. He presented to 160 first year medical students at Northwestern University for a class entitled “Cultural Dynamics of Medicine”.**
- **Hosting a mini-lecture series presented entirely by people with Aphasia. Presentations have included: Travels to Egypt by Dan Goffman, Ph.D., Travels to Israel by Barry Schaye, and Cruising the Panama Canal by Chuck Amato.**
- **Lobbying in Springfield, Illinois to help establish regional stroke centers. Fausto Ramos Gómez, stroke survivor with aphasia, went to the state capitol with the American Heart Association and distributed information about aphasia to 60 people.**
- **Partnering with Archeworks, an alternative design school, to develop aphasia-friendly products, like a wallet-sized communication flip-deck.**

Our plans for the future include:

- Going to Washington, D.C. for Lobby Day in Congress with the American Heart Association in late April and reporting back to our group (Fausto)
- Marching in the 5th Annual Chicago Disabilities Pride Parade in July (all of us)
- Publicizing our annual June Aphasia Day Event (all of us)
- Presenting to more medical students and classes of physical therapy or nursing students (Dr. Walsh)
- Checking for new legislation to promote aphasia awareness and funding for aphasia research (Fausto)
- Attending and presenting at the NAA convention in NY in June (hope to see you there!!)

To be continued... We are certain we will have a productive year and then some. To learn more about our groups and classes, please see the RIC Center for Aphasia Research website at www.ric.org/aphasia or Telephone: 312-238-6163 or email ebabbitt@ric.org



Chuck Amato and the RIC Center for Aphasia Research at the Disability Pride Parade, July 2007

The aphasia group facilitated by Mona Greenfield visited The Museum of Modern Art (MOMA) as part of our special access project.

Here are some photos of their experience.



We encourage other groups to take advantage of this wonderful opportunity by contacting the Group Services Department at (212) 708-9685 to arrange your visit at least 2 weeks in advance. Group visits must be scheduled on Tuesdays when the museum is closed to the public.



The aphasia group facilitated by Mona Greenfield visited The Museum of Modern Art (MOMA) as part of our special access project.

Here are some details about their experience.



Aphasia Group Visit to the Museum of Modern Art

On Tuesday, April 15, 2008, aphasia group members visited with Museum of Modern Art with educator, Gordon Sasaki. The opportunity to visit during a day that the museum was closed was special for participants. Also admission was free!

We visited Van Gogh, Monet, Matisse, Picasso and more. Members described and discussed the paintings and shared their personal feelings about the brushstrokes and themes of the paintings. They all liked Starry, Starry Night by Vincent Van Gogh and sang the song about this painting written by Don McClean. The pre-visit by Gordon to our group helped prepared members for what they would be viewing. Members requested future visits which have been scheduled.

The art theme facilitated word finding and important functional cognitive skills for the members of our group. They recalled painting and artists which were discussed during the pre-visit and express their feeling and thoughts about the paintings at the museum and in follow up therapy sessions and group.

Thank you Gordon Sasaki and the Museum of Modern Art for this spectacular experience.

CONGRESS ONCE AGAIN PROCLAIMS JUNE

National Aphasia Awareness Month!
National Aphasia Awareness Month!



On May 14, 2008 Senate Resolution 566 and House Resolution 1188 unanimously passed the House and Senate to proclaim June 2008 National Aphasia Awareness Month. The National Aphasia Association is indebted to Senator Tim Johnson of South Dakota and Congressman Edward J. Markey of Massachusetts along with their legislative staff for their sponsorship and efforts to bring this resolution to fruition once again.

These Congressional Resolutions are now part of the Congressional Record and can be used as advocacy tools to increase aphasia awareness throughout the year. Text of the resolutions can be found on our website www.aphasia.org

The NAA encourages everyone to write a letter to the sponsors of the resolution to thank them for recognizing the importance of increased public awareness and devoting their time to this important issue. Special thanks to NAA Board member, Dr. Paul Rao, for spearheading these efforts!

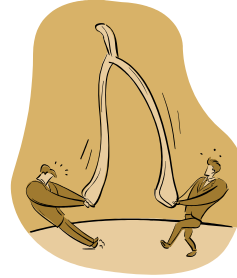


We want to feature information about

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.

NAA Wishlist



We need an LCD projector in order to do our Emergency Responder trainings in NY, NJ and Connecticut. These trainings will increase understanding of aphasia for firefighters, police officers and emergency medical technicians. Can you donate a projector and/or the funds so we can purchase one for the Association. You will be assisting us in our mission as we raise public awareness of aphasia.

If you interested in helping contact

Ellayne Ganzfried at Ganzfried@aphasia.org or (212) 267-2814



Barbara C. Martin
President

Lee Ann C. Golper, Ph.D.
Vice President Strategic Planning

Anna M. Barrett, M.D.
Vice President
Outreach & Organizational Development

Leonard Resnicoff, Treasurer
Vice President Budget and Finance

Martha Taylor Sarno, M.A., M.D. (hon)
President Emeritus and Founder

Alan Bandler, Esq.
President Emeritus

Mike Adler
Mary Boyle, Ph.D., CCC-SLP
Jose G. Centeno, Ph.D.
Steven Kessler, Esq.
Don A. Olson, Ph.D.
Phyllis Putter Barasch
Paul R. Rao, Ph.D., CCC-SLP
Josh J. Roth
Oliver Sacks, M.D.
Steven L. Small, Ph.D., MD
J. Tyler Entwistle

NAA Staff

Ellayne S. Ganzfried, MS, CCC-SLP
Executive Director

Amy Coble
Information/Administrative Coordinator

Joan Peters, Esq.
Fundraising Consultant

NEWS AND NOTES



⇒ Register Now for Speaking Out 2008-Brochures have been mailed and are also online. Limited affordable lodging available through NYU dormitory-Housing information is also on-line.

The NAA welcomes the following new

State Representatives:

Anne Loughridge-FL

Debbie Zabel-NJ

Sharon Pettiford-NC

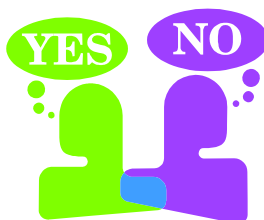
Karen Tourey-FL



We also welcome student interns-

Amy Schwinder, Jillian Bloom and Sarah Garabedian.

Your assistance is invaluable!



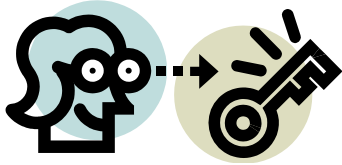
Can't attend?

Can't attend?? Why not sponsor a person with aphasia or a family member to attend the conference. We have a waiting list of people looking for sponsors.

Contact Ellayne Ganzfried at Ganzfried@aphasia.org

or (212) 267-2814

NEWS AND NOTES



Don't Miss Speaking Out 2008 on **June 19-21** at **NYU**! Go to www.aphasia.org to register now or call NYU at (212) 992-9380 or the NAA at (800) 922-4622

Art exhibition planned for Speaking Out - Are you a person with aphasia with artistic talent? We would love to display your artwork at the conference.

Email us at Ganzfried@aphasia.org or call (212) 267-2814



Plan an NAA Happy Hour in your area

One is scheduled in

NJ on June 10 at Just Jake's in Montclair-Go to www.aphasia.org and click on

News and Events for more information



June is National Aphasia Awareness Month- Posters are NOW Available!

**Hope you are planning your Aphasia Awareness Events!
Contact the NAA at naa@aphasia.org**