
Aphasia Center of California

Volume 7 Issue 1 ♦ Spring 2004

Aphasia Book Clubs: A Life Participation Approach to Reading

“We cannot hold a torch to light another’s path without brightening our own.”

-Ben Sweetland

by Patricia Terry Olson,
Stroke Survivor & Board Member,
Aphasia Center of California

Ed. Note: The Aphasia Center of California has recently been awarded a two-year grant by the Langeloth Foundation in New York to replicate its innovative Aphasia Book Club program. In a highly competitive process, the Aphasia Center of California was one of nine successful organizations, out of 55 initial submissions, funded by the Foundation.

Over the past five years, Aphasia Book Club members have read fifteen books and are now preparing to read

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Ellen Bernstein-Ellis (center-rear) leading a Book Club group.

the next book, *At Home in Mitford* (1998) by Jan Karon. In this book, Jan Karon writes about life in a small Connecticut town focusing on the life of a lonely rector. Ellen Bernstein-Ellis, an Aphasia Center of California (ACC) speech-language pathologist, guides book club activities and leads discussion for the two groups, which are based on level of aphasia.

The ACC’s Book Club provides members with writing and drawing exercises to help them understand the author’s ideas and by leading them through discussions of the books. Through the book club, members have regained the ability to enjoy the process of reading, which some

regrettably felt they had lost forever.

Members of the Aphasia Book Club receive a copy of the selected book in large print, an unabridged audiotape of the book, worksheets and chapter synopses, and weekly discussions with other members of the group. All of these items are included with the cost of the class. Some participants enjoy reading the book alone. Some prefer reading while listening to the audiotape. Some members enjoy listening to the audiotape only. One member worked with a volunteer who read the chapter synopses for him, subsequently allowing the member to participate

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Our Mission Statement: *The mission of the Aphasia Center is to encourage and expand communication and psychosocial well being for those with aphasia. We are dedicated to helping families and stroke survivors understand the ramifications of stroke and aphasia on their daily lives and to improve the quality of life for all those affected.*

Susie Altaffer: A Living Miracle

By Mary Jane Laufenberg
Stroke Survivor and
Board Vice President,
Aphasia Center of California

Every time I visit the Aphasia Center, I see miracles, miracles, and more miracles. My most recent miracle at the Center was a very special one! Accompanying a young, energetic stroke survivor, Susie Altaffer, was her partner—a beautiful yellow lab, “Savoy”, who is Susie’s guide dog. Susie and “Savoy” are definitely a double miracle! It is my pleasure to interview them and share their story with you.

Mary Jane: Tell me about your life before your stroke.

Susie: I was born in Paris, France, and lived there with my family until I was 9 years old. Then we all moved to Sao Paulo, Brazil. Once there, I developed diabetes and had to have my pancreas removed because it stopped working. After I graduated from high school, I moved to Arizona to be with my aunt and uncle. I missed Brazil a lot, so half way through college, I returned there and taught English as a Second Language to children. When I was 24, I lost sight in both my eyes but had eye surgery, which allows me to see large print books. I came to California 12 years ago to visit my brother and have been here ever since.

Mary Jane: When did you have your stroke and what do you remember about it?

Susie: I had my stroke on June 27, 2001. I was 45 years old. That

day, I had a very, very bad headache. As the day went on, people were having trouble understanding me and I couldn’t understand them very well either. My brother took me to the hospital and I don’t remember anything at all those first few days. As time went on, I was told I began to speak in Portuguese. English came back very slowly.

Mary Jane: Do you know what was the cause of your stroke?

Susie: The doctors said it was probably caused because I am a diabetic, have high blood pressure and I used to smoke.

Mary Jane: What were your favorite activities before and what are they now since the stroke?

Susie: Before my stroke, I worked a lot with my brothers in their wholesale distributor business. I got up in the morning, went to work, worked a long day, came home, had something to eat, went to bed and woke up for another workday. After my stroke, I have become happier. To tell you the truth, I have enjoyed not having to work so hard. It has been



Double miracles: Susie Altaffer and her dog Savoy

great to have my brothers as my brothers, not as my business partners. I have a good family and have met many new friends. Many people have helped me very much.

MOST OF ALL, I am so happy I was able to get “Savoy”, my guide dog.

Mary Jane: Can you think of anything that has been a benefit from having the stroke?

Susie: One of the best things that has occurred for me is that now, when I lie down to sleep, I fall asleep immediately and don’t wake up during the night I don’t have to worry

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Aphasia Center News

Aphasia (uh fay' zhuh) n: an impairment of the power to use or comprehend words, usually acquired as a result of a stroke and sometimes from head injury or a brain tumor. More than one million Americans have acquired aphasia.



"I jenti ferbis..."

relatives or friends that wish to donate, simply call Donate For Charity toll-free at (866) 392-4483 or donate on-line at www.aphasiacenter.org. We hope you'll take advantage of this new opportunity and help us expand our commitment to improving the quality of life for all those affected by aphasia.

Spreading the Word to Speech-Language Pathologists

Dr. Roberta Elman and Ellen Bernstein-Ellis presented papers at the American Speech-Language-Hearing Association convention in November in Chicago, IL. Dr. Elman presented two seminars at the convention: she reported on an international survey of aphasia services and provided clinicians with suggestions on how to include services related to life participation in their practices. Ms. Bernstein-Ellis and Dr. Elman also presented a poster on the Aphasia Center's innovative Book Club program. Aphasia Center of California

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Great News! The Aphasia Center Now Accepts Vehicle Donations

The Aphasia Center of California is excited to announce our brand new vehicle donation program. We've teamed up with Donate For Charity, a company that specializes in processing vehicle donations for nonprofit organizations. Donate For Charity arranges for vehicle pickup, handles all

the DMV issues, sells the vehicle at auction, and distributes the net proceeds to Aphasia Center of California. So if it's time to replace an older car, or if you have a boat and trailer that are just taking up space in the garage, consider making a donation. You'll avoid the headache of selling a used vehicle, help the Aphasia Center of California fund its ongoing efforts, and receive a receipt entitling you to deduct the fair market value of your vehicle as a tax deduction. When you're ready to donate, or if you have

Join our Second Annual "Walk to Talk" Raise Funds and Awareness!

What: The Aphasia Center of California's Second Annual "Walk to Talk" is a fund-raising event to raise funds for our programs. Our "Walk to Talk" will feature a 1/4 mile and 3 mile untimed walk/run.

When: Saturday, June 19th, 2004. Walk will begin at 10:00am.

Where: Lake Merritt, Oakland. Walk starts at the Downtown Oakland Senior Center at 200 Grand Avenue.

How: Companies and individuals, from walkers with kids to seasoned athletes to people with their dogs on leashes can participate in this event to benefit the Aphasia Center. Help the Aphasia Center by sponsoring an Aphasia Center participant, asking friends and family for donations, or joining us for the walk. Please contact Roberta Elman (510) 336-0112 to receive a walk packet or for more information.

Thank You to Our Generous Donors

July 2003–December 2003

If we have made any errors in this listing, please accept our apologies and contact us at (510) 336-0112.

Memorials

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Robert & Brenda Bowen

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Mary Boyle

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Angela Brock-Kyle &
Bernard Kyle

Louis F. Caslin

Dan & Diana Sullivan

Philip T. Clark

Barbara Clark
Susan J. Clark

John Corro

Twyla Corro

Carolyn Diller

Roy & Elinor Bell

Lillian Elman

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Stacie Raymer

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*This newsletter is a publication of
the Aphasia Center of California*

*Written and edited by Mary Jane Laufenberg,
Patricia Terry Olson and Roberta J. Elman*

Design and layout by Morris Older

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ACC 2003 Annual Report

2003 SERVICES

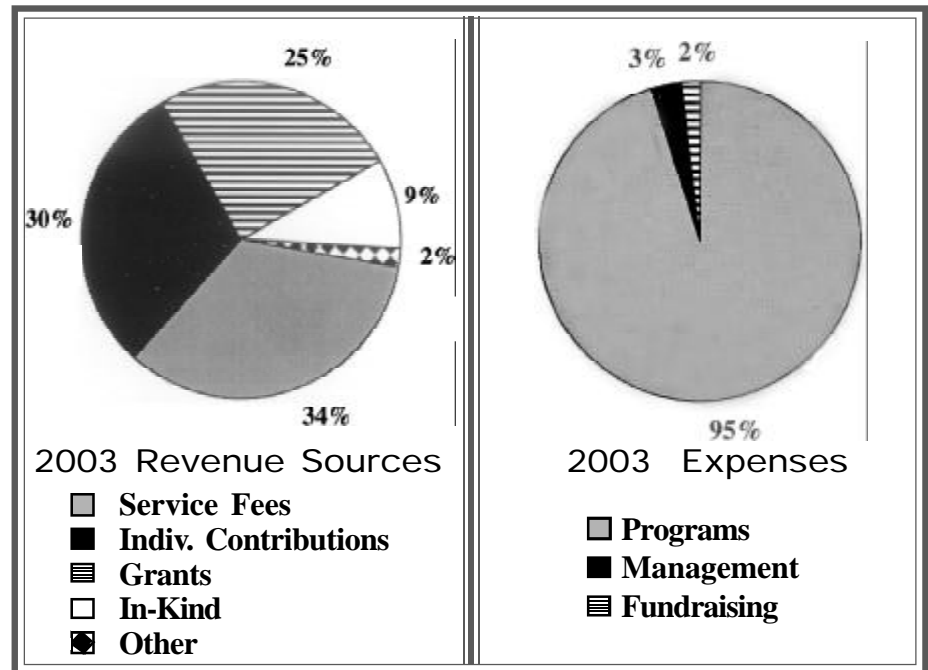
Total Visits: 5009
 Group Communication Treatment Visits: 2620
 Individual Speech-Language Treatment Visits: 163
 Reading & Writing Classes: 522
 Painting/Drawing Classes: 602
 Fitness & Relaxation Classes: 742
 Educational Stroke Group Series: 360
 Information & Referral (includes phone, mail, and e-mail): 1913
 Web site hits to date: 28,000+

ORGANIZATION & CORPORATE DONATIONS

Cerrito City Club
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 Dreyer's Grand Ice Cream
 Good Shepherd United Methodist Women
 International Association of Fire Fighters-Local 55
 Pat Martin Stroke Support Group
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 Infinity Salon with Dominic-Lafayette
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 La Strada Restaurant-San Pablo
 Long's Drugstore-Oakland
 Mother's Cookies-Oakland
 Movie Express-Oakland
 Mucho Wraps
 PacifiCare
 Pastino's Restaurant-Oakland
 Peet's Coffee & Tea-Oakland
 Purple Plum Restaurant-Oakland
 Rite-Aid-Oakland
 Safeway-Oakland
 Starbuck's Coffee-Oakland
 Svenhards Swedish Bakery-Oakland
 Terzetto Cuisine-Moraga
 Trader Joe's-Lafayette
 Uncle Chung's Szechuan Restaurant-Pinole

Ultimate Grounds-Oakland
 Zatis Restaurant-Oakland\

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Speech-Language Pathology Services: Ellen Bernstein-Ellis, Roberta J. Elman, Susan Adair Ewing
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 Computer Services: Steven G. Fry
 Newsletter Design & Layout: Morris Older

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City of Oakland, Downtown Senior Center

Thank You to Our Generous Donors

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ACC Book Club Replication

Continued from page 1

successfully in the discussions. Whatever works for each individual, according to the ACC staff, is great as long as they enjoy the books.

Dr. Roberta Elman explained that the book club was started as an extension of traditional reading and writing groups. This option incorporated the values and philosophy of the ACC into daily activities by giving members a choice of age appropriate classes as well as increased life participation skills. Dr. Elman noted that these are critical to the reintegration of aphasia survivors into the community.

A replication of the ACC's book club program has begun. The Langeloth Foundation, based in New York, has awarded the ACC a grant to expand the book club to four sites in North America: a university in Montclair, New Jersey; a medical center in Chicago, Illinois; and Aphasia Centers in Philadelphia, Pennsylvania



Lynne Tabor, Don Welcome and David Rose (left-right) at the ACC Book Club

and Toronto, Ontario. In March 2004, these sites will receive the first set of books for their reading groups. The ACC will provide these sites with a teaching manual, and curriculum materials developed by Ellen Bernstein-Ellis and many of the Aphasia Center's graduate student interns. After reading the book and completing the learning exercises, the

participants, volunteers and speech therapists will provide feedback on the process and materials to the ACC. This information is necessary for the ACC to get an impartial review of the materials before publishing them on the Aphasia Center of California's website, www.aphasiacenter.org.

One goal of the ACC's grant is to provide access of the book club materials to speech therapists anywhere in the world who would like to use them. A number of speech-language pathologists have reported their desire to start book clubs with individuals who have aphasia, but state that they lack the time to develop the necessary materials. The ACC's book club materials will allow them this unique opportunity.

If you are interested in joining the book club or would like to volunteer to help members in the book club, you may contact Dr. Roberta Elman at (510) 336-0112.

ACC News

Continued from page 3

staff remain dedicated to sharing clinical advances with others in order to help as many people with aphasia as possible.

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www.iGive.com/ACC**

Everybody shops. Think of how much money will go to the Aphasia

Center of California if supporters do some or all of their shopping online at www.iGive.com/ACC where up to 27% of every purchase is donated to the Aphasia Center of California. At iGive.com, membership is free and there is no extra cost or obligation to you. And iGive.com will currently donate an extra \$5 to the Aphasia Center of California for all new members! You can shop at over 240 merchants, including Lands' End, Gap.com, PETsMART, Barnes and Noble and more and help the Aphasia Center at the same time! Please go to: www.iGive.com/ACC

www.aphasiacenter.org

Susie Altaffer: A Living Miracle

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anymore. I don't even know where "Savoy" goes or what he does during the night. All I know is that he is right there and is very happy in the morning when I wake up.

Mary Jane: When and why did you decide to get "Savoy"? What was the San Rafael Guide Dogs for the Blind training like? How has "Savoy" affected your life?

Susie: I live in Alameda and, of course, was not working. Therefore, I had time for exercising by walking and listening to music. It became the best time for me to get a guide dog. In January of 2002, I sent my application in and was interviewed by the Guide Dog staff in May. I went to training and graduated with "Savoy" in September. I had no idea what I was going to learn or what kind of dog I was going to get but it was very exciting! By necessity, the training was dif-

ficult. Each day was long and challenging. I fell in love with "Savoy" on the day I got him. Because of my aphasia, it was very difficult for me to remember his name and it took me three days to do so. I am so happy that he has become a part of my life!

Mary Jane: Any special suggestions for stroke survivors (conquerors) today?

Susie: I think I take life as it is today. I am completely different from before my stroke although I wear the same clothes and wear my hair the same way. I don't work right now and don't really have a lot of money, but I don't have to worry about everyday things that aren't really important. When things get tough, I just take a look at where I am now and thank everyone and everything that have gotten me here. I have "Savoy", my friends and family that always keep me going!

Mary Jane: Can you tell me about

the benefits you've received at the Aphasia Center of California?

Susie: At the Aphasia Center, I am able to meet, discuss and talk to the staff as well as other people who have had strokes. I love to attend my group meeting each week where we all talk about our previous week. I also love the Book Club, which not only draws me into books which I would not have chosen to read, but it makes me think about each chapter and write my thoughts. It makes me listen to what other people think and causes me to think in different ways about the same thing. I love going to large Stroke Groups when different people are invited to talk to us about things such as physical techniques that might be helpful to us. I also appreciate the annual Aphasia Walk as we all try very hard to make the walk financially successful. Going to the Aphasia Center really helps us all to maintain a positive attitude!

Aphasia Center of California

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