



Spring 2006

The AlphaNetter is a publication of AlphaNet, Inc. AlphaNet, Inc. 2937 SW 27th Ave., Suite 305 Coconut Grove, Florida 33133 800- 577-2638, Fax: 305-442-1803 www.alphanet.org

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The AlphaNetter

A DAY AT THE BEACH

Sue Smith's Alpha-1 had progressively weakened her lungs and, as she awaited a transplant, her husband Doug found his job eliminated. Given the situation with Sue's health, the Pittsburgh, PA, couple decided it would be better for Doug to provide some of Sue's care and work from home. And so began their successful collaboration on the colorful and enjoyable book, "A Day at the Beach, How Absolutely Anyone Can Successfully Build Sand Castles and Build Even Better Beach Memories."

Sue has done well following her transplant at the University of Pittsburgh Medical Center, in spite of breaking an ankle (encased in special protective boot in photo) after a misstep during her daily speed walk. She and Doug continue to celebrate every day.

The book is available through many bookstores and coastal gift shops as well as on www.Amazon.com and www.EducationalBeachPress.com.



SUE, DOUG & A SANDCASTLE BUILT WITH FRIENDS ON THE JERSEY SHORE

OUTCOME STUDY

SUMMARY REPORT

TO BE RELEASED

With the participation of more than 1,000 Alphas, Phase II of the AlphaNet Disease

Management and Prevention Program Outcome Study has been completed. Final analysis of the data is being completed with the goal of publishing several articles in medical journals. The study was designed by the AlphaNet medical team, in conjunction with Drs. Michael Campos and Adam Wanner of the University of Miami in Florida.

"We were able to see dramatic improvements in a number of quality of life and healthcare cost measures," explained Robert A. Sandhaus, MD, PhD. "Prior to the study we had hoped to see at least a slowing in the decline of those with Alpha-1, but we've seen actual improvement."

A detailed report will be mailed to all AlphaNetters.

SIMPLIFY YOUR INFUSIONS

Alpha David Noyes from Ohio has designed a special rack for holding sterile water bottles upright while the fluid drains into the Alpha-1 Antitrypsin powder. The rack helps save infusion time by keeping the bottles from toppling and losing their vacuum. David was kind enough to donate a limited number of racks to the Alpha-1 Foundation.

For a \$50 contribution to the Foundation, racks are available.

Order while supplies last, by calling toll-free 877-277-7931.



In Memory

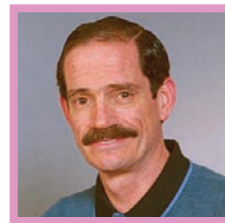
Sadly, the AlphaNet family recently lost two outstanding members. Phil Freeman and Randy Harwell served both the AlphaNet organization and their fellow Alphas with compassion and dedication. They will be missed by all.



Randy Harwell

February 10, 2006

AlphaNet Coordinator for South Carolina, Georgia and Tennessee, Randy lived in Louisville, Kentucky. A double lung transplant recipient in 1995, Randy worked for AlphaNet since 2002. He was devoted to AlphaNet and the cause of organ donation. Randy is survived by his wife Karen, three children and three grandchildren.



Phil Freeman

August 8, 2005

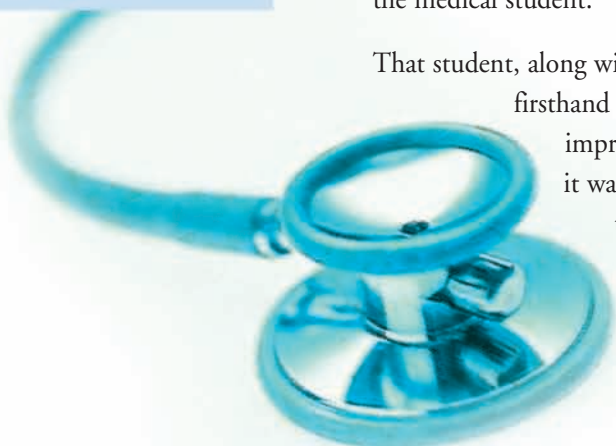
Serving AlphaNet since 2001, Phil was Coordinator for Arizona, New Mexico, Oklahoma, West Texas and Utah. An excellent golfer with deep religious conviction, Phil lived in North Central Kansas and is survived by his wife Anne and daughter Hilary.

GEORGIA ALPHA HELPS EDUCATE MEDICAL STUDENTS

Jerry Thurman, from Dalton, Georgia, hooked up his oxygen and started his three times a week walk around his local mall. On this particular day there was a health fair going on and Jerry noticed a young man in a kiosk, with an oximeter, watching him closely.

After he finished his routine, Jerry paid a visit to the kiosk to check his O₂ saturation; it was 88. After the young man asked what his liter flow was (6), this surprising data led to a question about what condition Jerry had. Jerry barely got the first part of Alpha-1 spoken before the young man finished it for him and lit up; he was a medical student and had a lot of questions for Jerry. Jerry explained about the Big Fat Reference Guide (BFRG) and AlphaNet and ended up giving his phone number and address to the medical student.

That student, along with two others, has visited Jerry several times to see the BFRG firsthand and learn as much as they can about Alpha-1. All three were impressed. They had studied Alpha-1 in medical school and thought it was so rare that they would never meet an Alpha. Now, thanks to Jerry, they understand much more about Alpha-1, and that it is not so rare.



CLINICAL ROUNDS

IMPORTANT WEBSITES:

Travel season is approaching and for those who take oxygen, check these sites:

Equipment & airlines that allow oxygen: www.oxygentogo.com

Rental of equipment & Inogen concentrator: www.choicehme.com

Air quality, updated daily: www.airnow.gov/index.cfm

NEW STUDY: Shortness of Breath for COPD Patients, conducted by the University of California, San Francisco and the University of Washington. Internet based so enrollees can participate from home. For information: www.managesob.org

NEW REPORT: Article discussing a clinical trial of inhaled cyclosporine for lung transplant patients, Jan. 12, 2006, New England Journal of Medicine

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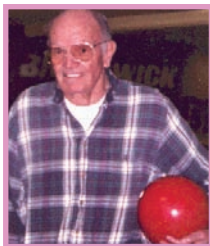
Alpha Teacher Leads Students to Rebuild Gulf Coast Housing

Bob Phillips, an Alpha from Vermont, is Assistant Technical Director at Spaulding High School & Barre Technical Center Campus. He is leading a group of Building Trades students to Waveland, Mississippi, to help rebuild homes devastated by Hurricane Katrina. The students have also worked hard to raise the money necessary to make the trip. Bob and the teens were recently featured on their local television news.

Bowling for Perfection

Alpha Norm Wilde, from Anza, CA, was featured in the San Diego newspaper, The Californian, for bowling a 300 game (that's a perfect score for all you non-bowlers). And, he did this at age 78, in spite of his breathing difficulties.

Norm bowls in two senior leagues and has many team members with medical disabilities. He feels bowling is very good exercise and also provides a tremendous support group. He says many of his team members survive "because of the bowling." Norm urges other Alphas to consider activities like bowling to keep active and develop lasting friendships. When describing

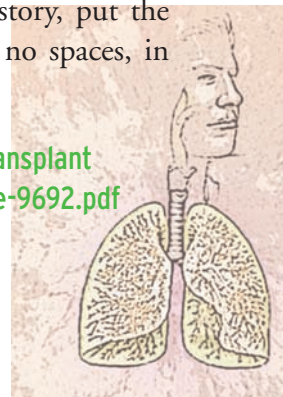


his "loving, caring supportive" teammates, he explained, "I have probably gotten more hugs and kisses than you would in a parked car."

Lung Transplant Survivor Story

Veteran police officer, SWAT team member and Alpha, Dennis Scott was featured in a recent article about lung transplant survival by Cedars-Sinai Medical Center in Los Angeles, CA. For a copy of the complete version of this positive and interesting story, put the following link, with no spaces, in your computer:

www.csmc.edu/pdf/TransplantLungTransplantFeature-9692.pdf






GET MOVING WITH TEAM ALPHA


May 19-21 
Greenbrier Trail Bike Ride/
American Lung Assoc.,
Snowshoe Mountain, WV


June 2-4 
Lake Tour Bike Ride/
American Lung Assoc.,
Lake Geneva, WI

June 16-18 
Santa Inez Valley, CA Bike
Trek/ American Lung Assoc.,
Wine Country near
San Diego, CA

June 16 - 21 
US Transplant Games/
National Kidney Foundation
Louisville, KY

June 17 
American Liver Foundation Walk,
Milwaukee, WI

September 15-17 
Autumn Escape Bike Trek/
American Lung Assoc,
Cape Cod, MA

September 16 
Asthma Walk/ American Lung
Assoc. Charleston, WV

September 17 
Asthma Walk/ American Lung
Assoc. Huntington, WV

For Team Alpha information
contact Mary Pierce at 888-883-2991
mpierce@alphanet.org for details.

Team Alpha is sponsored
by Talecris Biotherapeutics.



ALPHA-1 EDUCATION DAYS

July - Tennessee - Nashville

August - Wisconsin - Fond du Lac

September - University of

Florida - Gainesville

November - Illinois - Chicago

Call your Coordinator for more
information.

NEW SUPPORT GROUPS IN COLORADO & FLORIDA

Welcome Alphabeaters North of Fort
Collins, CO. Group leader is liver
transplant "miracle" Glen Perkins.
Contact Barb Pusey at 800-745-3004
bpusey@alphanet.org

Gayle Marriott of Lake Worth, FL
has revived the area support group.
One participant has reported it to
be "the warmest and liveliest
support group I've ever attended."
Contact Bob Campbell 888-399-0443
rcampbell@alphanet.org

REGISTER TODAY!

Alpha-1 Association 15th Annual National
Education Conference San Diego, CA
June 23 - 25

Registration deadline: June 8

For more information
contact: Cathey Horsak 877-346-3212
horsak@alpha1.org

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