



WINTER 2010

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The AlphaNetter

The *AlphaNetter* is a publication of AlphaNet, Inc.



AlphaNet Coordinators and staff met in Chicago in October to receive technology and clinical trial training and to celebrate 10-year employment milestones. At the meeting, AlphaNet recognized Patient Service Coordinators (right to left) Pat MacInnes, Patti Brown, Kay Swift, Gayle Tipper, Diana Patterson, Darrell Nall, Vicki Cameron, Kathy Haduck and Judy Rose (not pictured) with AlphaNet pins for 10 years of dedicated service.

"The Coordinators are the heart and soul behind AlphaNet's health management system and they have been the driving force in its development and implementation over the past 10 years," said John Walsh, President, "I know my co-founders, Sandy Lindsey and Susan Stanley, would join with me in expressing our heart-felt appreciation to each of them for their dedication to our community and commitment to our vision."

According to Bob Barrett, CEO, nearly one-half of the AlphaNet Coordinators have been with the company for at least 10 years. In addition to those honored, AlphaNet also recognizes the continued service of long-time employees Fred Walsh, Coordinator, Janis Berend, RN, Nurse Case Manager, and Terry Young, General Manager, who have been with the company more than 10 years.

"It takes a special type of individual to do this job and AlphaNet is proud to have such a highly respected group of Alphas serving the community," Barrett told the Coordinator team at the meeting. "You live your disorder every day, and you work to improve the quality of lives of the Alphas you serve. You are truly the embodiment of 'Alphas serving Alphas'."

AlphaNet also honored Jim Quill (IN, SC) with the Coordinator of the Year Award for his excellent coverage for coworkers during their absences. Barb Pusey (Zemaira, Western US) received the Nancy C. Ferguson Award for excellence in service to the Alpha-1 Community for her involvement in Alpha-1 Association committees and for actively promoting attendance to events and support groups. AlphaNet honored Diane Walsh with the "Alfie" Award for her dedication to improving the lives of Alphas, and Diane presented an award on behalf of AlphaNet and the Alpha-1 Foundation to Joe Zuraw, Talecris Biotherapeutics, for his continuous commitment to the Alpha-1 Community for over 20 years.



WHO IS THAT CALLING ME?

From time to time, you may receive AlphaNet calls from someone other than your regular Coordinator. AlphaNet employs a few At-Large Coordinators to cover for Coordinators who are ill, on vacation or are out for other reasons. At-Large Coordinators are all Alphas and receive the same training as Coordinators assigned to specific geographic areas. They are your resource when your assigned Coordinator is not available, so please be sure to return their call when they leave you a message. AlphaNet's current At-Large Coordinators include, Linda Caly, Celeste Morris and Jane Totten. Access their bios online at www.alphanet.org.

As a part of our disease management services, you will also be receiving a phone call once every six months from AlphaNet's Communications Specialist, Rebecca Lilian. She will administer data-gathering questionnaires to collect general information about how Alphas perceive their quality of life as they live with Alpha-1. As always, any information you share remains secure and completely confidential.

Participation in this initiative significantly adds to the body of knowledge about Alpha-1 and leads to improvements in care and treatment for all Alphas.

The Step Forward Study is a clinical research project designed to evaluate the effects of interventions and incentives that will increase the activity and fitness of Alphas. AlphaNet thanks all study participants for their ongoing involvement in this important research initiative.

All participants in the Step Forward Study have received a spirometer, calibrated and custom-configured to produce accurate test results according to their height, age, gender and other factors. Twice monthly (or following an exacerbation or worsening of lung disease), participants perform a spirometry test, the results of which are stored on the device's internal memory. Every three months, participants are asked to insert their spirometer into the provided cradle and back up stored test data onto USB flash drives, which are then returned to the AlphaNet corporate office in a postage-paid, padded envelope. Once the flash drives are received, AlphaNet's IT staff imports the data they contain into a secure, unified database through a proprietary software application.

Data is reviewed and analyzed by AlphaNet's medical staff throughout the duration of the study. Findings from this IRB-approved trial will benefit all Alphas, and will be presented first to the Alpha-1 community.

CLINICAL COLUMN

Cold Weather Reminders for the Alpha-1 Community

By Teresa Kitchen, BSN, RN, AlphaNet Clinical Nurse Manager

As the temperature plunges outside, remember these helpful hints:

Wear a scarf or cold-weather mask

Cold weather is very drying and can irritate your airways. Take the extra time to gather a scarf or mask before leaving your home. When you have this layer loosely over your mouth/nose area; it can warm and humidify your air, decreasing shortness of breath related to the "icy" cold air.

Exercise Indoor versus Outdoor

When the air outdoors falls into the single digits and even lower, and you still want to exercise, please remember to warm up prior to your walk. You should spend 15-20 minutes warming up indoors and wear multiple layers when leaving the house. There are also many exercises you can still do inside while watching the snow fall outside.

If you have a topic you think that all Alphas should learn about in the next issue of the AlphaNetter, please contact Lindsey Griffin at lgriffin@alphanet.org or 800-577-2638 ext. 243.

CAREGIVER'S EXERCISE REGIMEN GETS RESULTS



Caregiver Mary Louise (ML) Carlton (pictured left) and Alpha Helen (Cathy) Gould (pictured right) first met and became friends at a campground near Cook's Forest, Pennsylvania in 2002. For financial reasons, both women decided to sell their trailers and share Cathy's home in Indiana, Pennsylvania starting in the fall of 2003.

At that time, Cathy had been in and out of hospitals 2-3 times a year. ML, a retired Physical Education teacher, set a goal to keep Cathy out of the hospital for three years by encouraging her to exercise. ML used her background to create workouts and both women joined the local YMCA in 2004. In the beginning, Cathy's lung function was at 28% and she could only walk a few

minutes on the treadmill at a low speed. She began using the stationary bicycle and, eventually, ML introduced her to the weight room. Both women continued to workout 4-5 times a week. In three years time, Cathy's lung function had increased to 36% with no hospital stays. In 2006, Cathy began using oxygen at night and during exercise. She started attending the Butler Pulmonary Rehabilitation Center in Kittanning, Pennsylvania in May of 2009. Her lung function has since increased to 39%.

"As a caregiver, I think one of the best things you can do is encourage exercise," says ML, "I am proud of what I do. It's rewarding, but I make sure to find time for myself so I don't wear out. Cathy has a wonderful attitude; she keeps me positive. We've ended up being very best friends."

"I think ML does so much more than she even realizes. She had to push me into exercising and now it feels so good. We are both excited about my progress. Although, sometimes I have to remind ML that I'm still the one doing all the work," Cathy quips.

Avoid Fireplaces or Wood Burning Stoves

Alphas are more susceptible to smoke-related problems. Both types of wood burning can expose Alphas to irritation in their airways.

Don't Over Exert Yourself

If you must go outside, work slowly and be aware of the windchill factor. Ask for friends/family to assist with the clearing of snow/ice from driveways and walkways. Place sand or kitty litter on these areas to increase your footing. Being outside for too long in cold weather can lead to severe shortness of breath.

Hand Washing

Frequent and thorough hand washing, specifically after touching surfaces used by others who have been coughing or sneezing, can greatly reduce the potential for infection during this flu and cold season.

Ill Family Members

Remember that you may need to limit your contact with family members who have a known respiratory illness, especially young children/grandchildren who attend daycare. As we all know, those children are at a higher risk for spreading illness. I'm a mom to young children and this is something that we work on all the time to decrease the illness in our home. As always, stay warm and healthy this winter season!

AlphaNet Employment Opportunity

Do You Have What It Takes?

Applications are currently being accepted for employment as AlphaNet Patient Service Coordinators. Interested Alphas should be dedicated, organized professionals who are able to travel and demonstrate strong computer and communication skills.

Send resumes to
humanresources@alphanet.org

AlphaNet welcomes new Coordinators Linda Caly, Celeste Morris and Jean McCathern. AlphaNet has trained Linda, Celeste, and Jean in health management, support systems and the facilitation of infusion supplies. They look forward to meeting, educating and counseling other Alphas.



Linda Caly was diagnosed with Alpha-1 in 2000. She recalls, “I was the first in my family to be diagnosed so it became important to me to educate myself and others.” Since then, Linda has been involved in her local support group, has participated in focus groups and has toured both the Zemaira and Prolastin production facilities.

“The process and technology it takes to create our therapy is incredible to me,” she says, “and therapy is only one aspect of a comprehensive health management plan. We have so many tools available to assist us in managing this disease; it’s just a matter of identifying and utilizing them. As a realtor, I spent 33 years educating people about the home-buying process and helping them to make good decisions. I look forward to educating my fellow Alphas and their families about

Alpha-1 to help them make the best decisions for themselves.”

Linda resides in Streamwood, Illinois where she enjoys cooking, gardening and walking outside when the weather is nice. Linda has three cats and no allergies, which is a relief, since she loves animals. She is also an avid traveler and especially enjoys the beaches in Mexico.

WHO'S NEW AT ALPHANET?

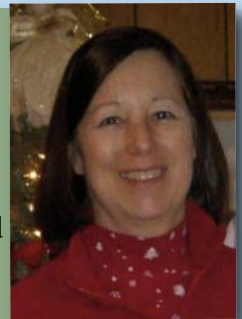


After 10 years infusing Prolastin and two lung transplants, the first in 2002 and the second in 2008, Celeste Morris has received a thorough education in life with Alpha-1. Celeste was diagnosed with Alpha-1 in 1989,

when at a neighbor’s recommendation she visited a pulmonologist at Loyola University Medical Center. Prior to that, three physicians were unable to accurately diagnose her and had told her she needed to get in shape.

“It’s a tremendous task to manage a chronic illness, *I know*,” she says. “Having someone there to help you order your medications, track your progress and to encourage you is invaluable. You have to learn the ropes with this disease and I am here and ready to help.”

With experience in interior design, sales, marketing and extensive home renovations while raising children, Celeste is used to coordinating projects and offering direction. Celeste currently lives in Chicago, Illinois and has two grown children. In her spare time, she loves to read, go to the movies and travel.



Jean McCathern was diagnosed in 2004, after repeated bouts of pneumonia caused her to consult a pulmonologist. She quickly acclimated to the Alpha-1 community and became a support group leader in Pennsylvania only three months after her diagnosis.

“I’ve learned more about Alpha-1 by helping others than I would have ever learned on my own,” Jean explains, “Now I am a member of a subcommittee for Clinical Resource Centers with the Alpha-1 Foundation, which has given me more opportunities to meet people who are involved with treating Alphas. I was also able to travel to North Carolina in 2008 to see how Prolastin is made. There are so many people working for the good of our community, and I am excited to be a part of what AlphaNet is doing to improve our quality of life.”

Jean brings with her extensive managerial and consulting experience in public and military environments. She has worked for the Pennsylvania Department of Transportation and the U.S. Navy National Maritime Intelligence Center. She spent 25 years in the Air Force and retired as Chief Master Sergeant.

Jean currently resides in Highspire, Pennsylvania with her faithful companion, Fred, a 9-year-old Chihuahua. She has one daughter, Laura Doty, whose husband is currently deployed to Iraq, and three grandchildren, Noah, Allyson and Jason.

Alpha Birder Explores Alaska

Avid birder Bob Cooper hasn't given up on his favorite hobby; he has just learned to adjust. He is pictured here on St. Lawrence Island, Alaska. Three miles behind him is the town of Gambell, population 650 (96% Eskimo), and forty miles west of Gambell are the volcanic mountains of the Russian Far East.

"This is something I love doing," Bob says, "and I'm just not willing to become a couch potato. 'No guts no glory' I've always said and I mean it."

Bob is outfitted for the trip with four layers of clothes, an oxygen tank on the ATV and the cannula under his nose. Notice the binoculars around his neck and the spotting scope tied to the front of the ATV. The medical clinic in Gambell gave Bob free oxygen, which he paid to have flown in from Nome.

According to Bob, "Life is good... We saw 20 species of birds that were LIFERS (we've never seen before). Plus we saw whales, walruses, Arctic foxes and seals. It's a real adventure."

Bob's career and hobbies have always kept him outdoors. He spent 26 years teaching Forest Resources Technology at the community college level. In the 1980s, he worked summers as a Ranger Naturalist at Grand Teton National Park in Wyoming, where he led nature walks and natural history canoe trips and gave evening programs. The valley in the Tetons is 7,000 ft. above sea level and each summer Bob came down with a respiratory infection when moving from his home in Oregon.

In 1987, Bob climbed Mt. Whitney at 14,496 ft., the tallest mountain in the lower 48 states, with his wife



Beverly and their daughters. Five days into the week-long backpacking trip, Bob came down with what he assumed to be altitude sickness. As a life long non-smoker, it never occurred to him that he had emphysema. Bob and his family reached the top, although Beverly and their daughters had to carry his gear the rest of the way. Finally 10 years later, with over 25 years of seeing

doctors for respiratory problems, he was accurately diagnosed with Alpha-1.

Bob retired in 1997 when his Alpha-1 began interfering with his job, but Bob and his wife continue to plan trips designed to bird watch and enjoy the plants, animals, history and geology of natural locations.

"I'm not cavalier," Bob says. "I'm a real planner. I take all my medicine on my trips. I am on oxygen almost 24/7, and I have a portable oxygen concentrator that I take with me wherever I go. I am very fortunate to have a wife who is such a tremendous caregiver. She is always ready for a new adventure in the natural world."

In 1997, when he was diagnosed, Bob and Beverly had already seen about 200 species of birds in the United States. Over the last 13 years, their list of birds seen has grown to 625 species.

"We're going back to Alaska in 2010, this time to Adak Island and the Pribilof's," Bob says. "We're going to keep on doing this until I can't anymore. 'No guts no glory'. That's how we're living and it is quite a ride."

Alpha-1 Association Education Days

co-sponsored by the Alpha-1 Foundation

March 6

Alexandria, Virginia

April 17

Atlanta, Georgia

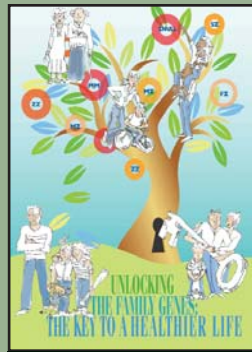
August 28

Des Moines, Iowa

September 25

Las Vegas, Nevada

To find out more about conferences and support groups, visit the Alpha-1 Association website at www.alpha1.org or call toll-free: (800) 521-3025.



Alpha-1 Association National Education Conference

June 11 - 13
Orlando, Florida



Jim Quill (IN, SC) receives Coordinator of the Year Award from Dr. Sandhaus, Bob Barrett and Terry Young.

Alpha-1 Foundation Event Calendar

March 13 - Celtic Connection
Boston, Massachusetts

April 17 - Salt Lake City Marathon:
Half Marathon
Salt Lake City, Utah

April 30 - Alpha-1 Foundation
Celebration of Life
Indian Creek, Florida

May 8 - 3rd Annual New York & New Jersey
George Washington Bridge Walk
New York, New York

May 18 - AlphaOkies Silverhorn
Golf Tournament
Oklahoma City, Oklahoma



Coordinator, Barb Pusey (Zemaira, Western US), receives Nancy C. Ferguson Award from Dr. Robert Sandhaus, Medical Director, Bob Barrett, CEO and Terry Young, General Manager.

To find out more about these or other events in your area, log onto www.alphaone.org or call toll-free: (888) 825-7421, ext. 248.


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