

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

COORDINATORS:

Gayle Allison Tipper 877-982-5742
gallison@alphanet.org (NC, VA, WV, DC)
Roger Bray 877-227-7914
rbray@alphanet.org (KY, IN)
Patti A. Brown 877-264-7470
pbrown@alphanet.org (TX)
Victoria (Vicki) S. Cameron 888-526-9077
vcameron@alphanet.org (ME, NH, VT, Volunteer)
Shirley R. Dennis
sdennis@alphanet.org
Kathleen (Kathy) A. Haduck 800-813-4494
khaduck@alphanet.org (DE, PA)
Kay Kinsel Swift 877-742-9078
kkinsel@alphanet.org (MT, NE, ND, SD, WY, CO)
Patricia (Pat) E. MacInnes (877) 277-7931
pmacinnnes@alphanet.org (NY)
Diana Patterson (888) 399-0443
dpatterson@alphanet.org (FL, PR, USVI)
Mary K. Pierce 888-883-2991
mpierce@alphanet.org (OH)
Barbara Pusey 800-745-3004
bpusey@alphanet.org (Zemaira USA)
Jim Quill 888-795-6393
jqull@alphanet.org (At Large)
Judy K. Rose 877-860-8694
jrose@alphanet.org (AZ, NM, At Large)
Jodi Roth 877-662-4774
jroth@alphanet.org (MN, WI)
Sandy L. Singleton 877-898-8630
ssingleton@alphanet.org (AK, CA, HI)
Kathleen (Kathie) D. Sivesind 866-244-1026
ksivesind@alphanet.org (NV, WA, OR, ID, UT)
Marta C. Strock 866-762-1850
mstrock@alphanet.org (Maryland & At Large)
Jane Totten 866-477-1552
jtotten@alphanet.org (GA, SC, TN)
Douglas (Doug) K. Turley 877-943-9828
dkturley@alphanet.org (IA, KS, MO)
Elizabeth (Liz) A. Veronda 888-723-9487
lveronda@alphanet.org (IL)
Marilyn Wagner 866-556-6622
mwagner@alphanet.org (AL, AR, LA, OK, MS)
Fred C. Walsh 800-791-3194
fcwalsh@alphanet.org (MA, RI, CT, NJ)

STAFF:

Robert C. Barrett, Chief Executive Officer
800-577-2638 ext. 229 rcbarrrett@alphanet.org
Robert A. "Sandy" Sandhaus, MD, PhD, FCCP,
Medical Director, Executive VP,
800-577-2638 ext. 226 rasanthaus@alphanet.org
Terry L. Young, General Manager
800-278-1804 tlyoung@alphanet.org
Bonnie S. Boyd, RN, Director of Disease
Management & Clinical Research
800-577-2638 ext. 253 bboyd@alphanet.org
Janis G. Berend, MSN, C-ANP, Nurse Case Manager
800-577-2638 ext. 220 jberend@alphanet.org
Teresa A. Kitchen, BSN, RN, Clinical Nurse Manager
888-553-0093 tkitchen@alphanet.org
Sarah Phillips, Executive Assistant
800-577-2638 ext. 243 sphillips@alphanet.org
Melissa Grenadir, Human Resources Manager
800-577-2638 ext. 247 mgrenadir@alphanet.org
Laura L. Larios, Accountant
800-577-2638 ext. 209 llarios@alphanet.org
Edward J. Parker, IT Manager
800-577-2638 ext. 257 eparker@alphanet.org

The AlphaNetter

The AlphaNetter is a publication of AlphaNet, Inc.



Joyce Finch wastes no time in retirement finishing up a quilt wall-hanging in the Victorian Stars pattern by Debbie Beaves. She plans to display the quilt in her home and has used spring colors because she is "ready" for the season to start.

JOYCE FINCH RETIRES WITH GRACE.

One of the first four AlphaNet Coordinators, Joyce Finch, retired March 1st, after a long and successful second career with AlphaNet.

When Joyce was diagnosed she was given the name of two other Michigan Alphas; one of those was Mary Pierce. It was Mary who first told her about AlphaNet and she immediately called with questions. Initially starting as a volunteer and working to help find a cure, she became a full-time Coordinator in 1997.

Prior to joining AlphaNet, Joyce owned and operated a garden center, a job that meant working long hours seven days a week. She brought that same energy, love of people and skill set to her work as a Coordinator.

"My job has been wonderful, the Alphas have been so nice and that's what I'll miss the most, talking to people every month," said Joyce.

At 71, Joyce says she is ready to retire and her family is excited. A resident of Greenville, Michigan, Joyce and her husband have three grown children and four grandchildren. She's always enjoyed traveling and camping throughout Michigan and now plans to do more, including a winter escape to the warmer climate in Florida. When it's too cold to travel you can find Joyce quilting and sewing.

"Being one of AlphaNet's very first Coordinators, Joyce called many Alphas across the country, not just Michigan, and several of those Alphas ultimately became AlphaNet Coordinators," explained Terry Young, AlphaNet's General Manager. "She became known as 'The Coordinator's Coordinator.' As a result, many of our Coordinators today emulate Joyce's nurturing, yet professional service. In this way, Joyce has been an integral part of the growth of AlphaNet."

AlphaNet Grant Helps Fund New Genetic Counseling Center



In 2007, the Alpha-1 Association Genetic Counseling Center was launched for those with Alpha-1, their families, physicians and healthcare professionals. Located in Charleston, SC, the Center is housed at the Medical University of South Carolina (MUSC). Dawn McGee, MS, CGC, was recruited by MUSC as a board certified genetic counselor.

McGee's credentials include an undergraduate degree in biology from Villanova University and a Masters in Genetic Counseling from Arcadia University, both in Pennsylvania. She also has extensive background experience with caregiver issues.

The Center was established by seed grants from Talecris Biotherapeutics and AlphaNet. Operating costs through 2008 have been funded by grants from Talecris Biotherapeutics and CSL Behring.

*Center hours are from 8 – 5 EST and after hours a message can be left.
Call toll-free: 1-800-785-3177.*

There is no charge for consultations and strict confidentiality is a priority. Callers can inquire about any aspect of Alpha-1 including gene inheritance, symptoms, testing, treatments, support groups and more.

HOT OFF THE PRESSES!

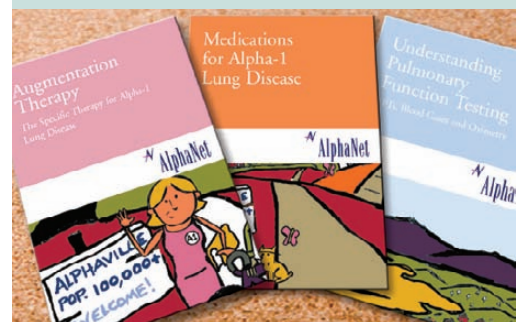
NEW SPECIAL TOPIC REFERENCE GUIDES AVAILABLE

Three new special topic brochures have been added to the AlphaNet library. **Medications for Alpha-1 Lung Disease, Augmentation Therapy and Understanding Pulmonary Function Testing** are now available.

Previously existing topics are also still available and include:

- **Traveling with Alpha-1**
- **Oxygen Therapy**
- **Understanding Pulmonary Exacerbations**
- **Staying Healthy/Management of Environmental Risk Factors.**

The guides offer focused information on single topics and have both included and expanded on the material in the Big Fat Reference Guide™. For copies, call AlphaNet at 1-800-577-2638 and ask for extension 243.



SPRING IS IN THE AIR

And that means pollen. To get information about your local pollen counts, contact www.pollen.com. Via e-mail they will send you an Allergy Alert™ two-day forecast for any US ZIP Code, whenever levels reach 4.0 on a scale of 0 – 12. Yahoo! Widgets and Google Gadgets offer free PC applications to monitor pollen activity. For information about pollen producing plants in any U.S. County, go to www.pollenlibrary.com and put in the ZIP code you are curious about. For additional information, visit the site of the American Academy of Allergy, Asthma and Immunology: www.aaaai.org and click on "pollen counts" for information in the U.S., Canada and Argentina. For European counts, in English, check out www.polleninfo.org



CLINICAL CORNER

Infusion Supplies and Alphas

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

Many Alpha patients receive augmentation therapy at home, some self-infuse and others have a registered nurse administering their therapy. In order to make dealing with supplies as easy as possible, here are a few things to remember:

- **Make individual weekly infusion packets.** Place all of the infusion supplies needed for a single infusion in a clear plastic bag. Make one supply packet for each of your infusions until all or the majority of your supplies are packaged. This allows you to determine immediately how many weeks of supplies you have and decreases the time needed to take a supply inventory for your AlphaNet Patient Services Coordinator.
- **Keep all of your infusion supplies in one area of your home** to eliminate any confusion.
- **Always keep a FEW extra items on hand** for back-up usage and communicate the types and numbers of these back-up items to your AlphaNet Coordinator.
- **Please tell your Coordinator** if your type of IV access changes. For instance, if you normally infuse peripherally (in the hand/arm) and then switch to a central line (Port), the type of supplies you'll need for your infusion changes. Your AlphaNet Coordinator will change your order to reflect the correct supplies.
- **Be sure to communicate with your Coordinator** well in advance if you have different or special supply needs for traveling.
- **Advise your Coordinator** if you have supplies that you or your nurse no longer uses in your home. Your Coordinator can advise you about what should be done with them.

Every three months your AlphaNet Coordinator records a supply inventory provided by you or your nurse. It is essential that you give your Coordinator an accurate count of each of the supplies items that you have on hand in your home at the time of the inventory. Please do not provide an order of what you think you will need. Your Coordinator will be able to discuss with you the next order period and the delivery date of those infusion supplies. I stress the importance of this so that the need for "interim orders" is reduced or eliminated and so that there is no interruption in the infusion of your augmentation therapy.

If you or your nurse needs assistance with infusion supplies, please feel free to contact your AlphaNet Coordinator or me. I am always willing to assist in teaching patients or to contact your nursing agency for education on infusion supplies or any questions about your augmentation therapy.

IF YOU HAVE ANY QUESTIONS OR A CLINICAL TOPIC YOU THINK THAT ALL ALPHAS SHOULD LEARN ABOUT IN THE NEXT ISSUE OF THE ALPHANETTER, PLEASE CONTACT TERESA KITCHEN AT TKITCHEN@ALPHANET.ORG OR 888-553-0093.

Did You Know...

Men, not just women, need to pay attention to their bone health.

According to the National Institutes of Health, one of four men and one in two women will have an osteoporosis-related bone fracture. Next year, the National Osteoporosis Foundation is planning to release guidelines for men's bone health. In the meantime, medical experts have recognized several risk factors that increase the likelihood men will develop osteoporosis. They include being more than 56 years of age, less than 175 pounds and suffering from COPD. Smoking, excessive drinking and some drugs, such as steroids and those used for prostate cancer, can also put men at higher risk for the bone disorder. Good nutrition, calcium, vitamin D and exercise can all help reduce the risk of osteoporosis.

AMAZING ALPHAS:

JERRY

ANDREA

ALEX

With oxygen tanks on-board, Jerry peddles through the NE Georgia countryside near his home.



JERRY Thurman has battled his health since childhood. Since he lived on a farm, one diagnosis for his early lung problems was even blamed on the chickens he worked around. Eventually he obtained information that led him to question if he had Alpha-1. The diagnosis was confirmed in 2001, at age 59. After a friend searched the internet to find who made Prolastin, Jerry contacted the drug manufacturer and learned about AlphaNet. Once he connected with AlphaNet, the Patient Services Coordinators helped him cut through the red tape and obtain some of the then elusive drug.

In spite of this victory identifying his disease and finding the augmentation therapy drug, his doctor told him although the medicine was good it would not keep him alive. He was going to have to put up a hard fight to survive. So Jerry got a treadmill and started walking; at first, he was only able to last five minutes at a time.

Circumstances were tough for Jerry, but he kept battling and working his way back up the ladder whenever his health would slide. AlphaNet Coordinators kept checking in, encouraging and helping him all along the way. He began adding long outdoor walks to his regime and one day was chatting in the park with an 81-year-old man who was riding a bike. Jerry was intrigued; maybe he could also ride a bike.

His daughter and son-in-law both ride motorcycles and they insisted on helping Jerry select the perfect bike. Outfitted with his new 24-speed bike, complete with headlights, horn and racks for his oxygen tanks, Jerry began to ride . . . and he kept riding. His bike now has more than 1,000 miles on it and he generally rides at least ten miles, often two or three times a day.

Now a fixture around his Chatsworth, Georgia home, Jerry attends motorcycle rallies on his bike and even rolls up to the drive-through window of the local drugstore to pick up his prescriptions. This great grandfather has beaten the odds and fought many obstacles to survive.

Through it all, "AlphaNet has helped me so much," said Jerry. "They saved my life."

TELLING HER STORY

Andrea Maechtle felt she needed a fresh start. Living in Chicago, and working 12-to-14 hour days as an inventory and accounting manager in the food service industry, became tougher each of the six years since her diagnosis of Alpha-1.

Trying to juggle work, being a single mother and manage her disease were causing her such stress that her infusion nurse suggested she see a psychologist. She found a psychologist who also suffers from a chronic illness and had developed a specialty in helping patients cope. It didn't take long before the two women began brainstorming how they could help others.

They formed an organization called Caring Voices (www.caringvoices.info), to bring together some of the 41 million people with chronic illnesses that are limited in their daily living activities. The group started a support group, sponsors an interactive website and began producing a documentary to help people learn to overcome the challenges they face living with chronic illness.

In the meantime, Andrea had taken control of her life. She retired, pulled up stakes, moved across the country to Georgia to be near family and adjusted her physical activities from softball and volleyball to swimming and reading. Now in Statesboro, Georgia for three years, she is seeing the documentary project finally come to a long-anticipated completion.

The team initially labored to produce the documentary independently, but The Art Institute of Chicago got wind of the project and assumed the responsibility for production and direction. The program features four individuals who have faced their chronic illnesses head-on, including one each afflicted with MS, ataxia, a brain tumor, and Andrea with Alpha-1. They talk through the stages of learning to accept and cope with their situations as well as tips on navigating the healthcare system and how nurses help and care for their patients. A special premiere is scheduled for May 10th in Chicago.

Andrea said she has really enjoyed the venture, and the documentary has been "a good and healing project" for her. Through it all, she has maintained her lung function at the same 23 percent level as her initial diagnosis and is ready to face new challenges.

Taking a break from reviewing video and editing, Andrea poses with an early version of the documentary about living with chronic diseases.



Photo by Rick Brady

EXPRESSING PASSION THROUGH ART

At 55, **ALEX** Harrah is living the artistic life he used to dream about. A welder by trade, Alex had changed careers long before his Alpha-1 diagnosis in 1991. A resident of Houston, he eventually had his own picture framing shop, which was more in keeping with his artistic side, before going on disability about seven years ago.

He now lives in an apartment in one of Houston's trendy, artsy neighborhoods and rides his Deco-style scooter around the area. "I was always a hippie at heart," explained Alex, who favors wearing tie-dyed t-shirts.

These days, he has found a new passion through his art. He specializes in car art and in graphic visualizations of anti-tobacco messages. Alex's work has been featured in national Art Car magazines, in a film about Houston, and in the pages of the Alpha-1 Foundation magazine.

Those outside Houston may not be familiar with the city's annual 300-car, Art Car Parade and ArtCar Museum. Car Art is big in Houston, but not all of Alex's masterpieces are mobile. He frequently uses pieces of cars to create his mixed media pieces to hang on walls.

In 2003, his car, titled Cigs-Kill, won Best Art Car in the Parade, and, after he drove it for a few years, was subsequently purchased by the ArtCar Museum for permanent display.

Alex misses having an Art Car and has recently started work on a '68 hearse that will carry another anti-smoking message.



A SELF-PORTRAIT BY ALEX, MADE WITH A TOY CAR, SILVER LEAF, TIE DIE AND HIS IMAGE, FORMED OUT OF BENT WIRE, SOLD FOR \$1,200 TO A COLLECTOR. IF YOU LOOK CLOSELY YOU CAN SEE HIS CANULA AND THAT HIS BODY IS REPRESENTED BY A LUNG.

HEARD ON THE STREETS...

ALPHANET PHARMACEUTICAL PARTNERSHIPS WORKING WELL FOR ALPHAS

Thomas Smirniotopoulos, MD, a pulmonary specialist from Alexandria, Virginia, recently shared his positive reaction to the AlphaNet-Talecris relationship. He was approached by a new patient who needed help adjusting her infusion therapy. The patient reported having a regimen that was too intense and learned from her AlphaNet Patient Services Coordinator her therapy could probably be adjusted. Since her existing physician would not consider any new information or change, she sought another medical opinion.

Once Dr. Smirniotopoulos completed his diagnostic work-up on the patient he spoke with staff at Talecris and initiated a more reasonable schedule for augmentation therapy.

"The relationship between Talecris, AlphaNet and patients with Alpha-1 is an excellent example of good stewardship on the part of the pharmaceutical industry," said Dr. Smirniotopoulos. "The situation was managed very well."

The patient is now clinically doing very well, back on a more reasonable infusion schedule and everything is being successfully managed between her insurance company, infusion provider and AlphaNet.

TRANSPLANT GAMES SET FOR JULY IN PITTSBURGH

Registration has started for this summer's Transplant Games to be held July 12 - 15, in Pittsburgh, PA. Alphas from Oregon, Illinois, Virginia, Ohio, Michigan, Utah, South Carolina, New Hampshire and Pennsylvania have already committed. They will compete in a range of sports including: golf, cycling, track & field, race walking, swimming, racquetball, volleyball and bowling. The Alpha-1 Foundation will have a limited number of scholarships for those who wish to attend.

Those interested in more information or participating should contact Mary Pierce at 1-888-883-2991 or mpierce@alphanet.org






Calendars:

Alpha-1 Foundation & Team Alpha

May 10
1st Annual GW Bridge Walk-a-thon
Mara Center for Lung Disease at
St. Luke's Roosevelt Hospital, NY

May 15-18
 21st Annual Greenbrier Trail Bike Trek
Greenbrier, WV

May 16
Alpha Okies Silver Horn Golf Tournament
Oklahoma City, OK

May 17
Bike Trek for Alpha-1
East Lyme, CT

JUNE 27-29
2008 Breathe Easy Ride of Santa Barbara County's
Wine Country
Santa Inez, CA

SEPTEMBER 12
24th Annual Autumn Escape Bike Trek
(aka "Escape to the Cape")
Plymouth to Provincetown, MA

To find out more about these or other events
in your area, log on to www.alphaone.org or
call toll-free: 1-888-825-7421, ext. 248.

Alpha-1 Association Programs & Activities

MARCH 29
Regional Support Group Meeting
Jackson, MS

APRIL 26
Alpha-1 Education Day
Chicago, IL

June 20-22
17th Annual Alpha-1 Association National
Education Conference
St. Louis, MO

August 16
Regional Support Group Meeting
Lebanon, NH

August
Alpha-1 Education Day
Ann Arbor, MI

September 20
Alpha-1 Education Day
Chapel Hill, NC

September 27
Regional Support Group Meeting
Las Vegas, NV

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

Be a part of the largest gathering of Alphas
and their families anywhere in the US.

Call today and register: 1-800-822-3535.

June 20 - 22 - 17th Annual Alpha-1
Association National Education Conference, St. Louis, MO



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YOUR SPRING
ALPHANETTER IS HERE

