



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

**COORDINATORS:**

**Gayle L. Allison** 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  
**Joyce Finch** 888-225-9012  
jfinch@alphanet.org (MI)  
**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  
pmacinn@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 rbarrett@alphanet.org  
**Robert A. "Sandy" Sandhaus, MD, PhD, FCCP**,  
Medical Director, Executive VP,  
800-577-2638 ext. 226 rasandhaus@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.

*HAPPY HEALTHY NEW YEAR!!*



## AGE IS NO BARRIER FOR THESE ALPHAS

Many diagnosed with Alpha-1 are often mistakenly under the impression they will not live a long and productive life. This notion is often a result of misinformed physicians who don't have a complete up-to-date understanding of Alpha-1.

"So many of us were not expecting to live into our 70's and 80's and some not even to our 60's," explained AlphaNet Coordinator Judy Rose. "It's just not the case, we see many patients living long and productive lives."

One example is Maryland resident, Isabel Baynes. Isabel, a very active 78, hasn't let living with Alpha-1 slow her down. She recently painted her barn and frequently can be found working her expansive property, weeding, planting, cutting down trees for her curly willow business, even jumping on her tractor to pull up tree stumps.

She keeps busy with a wide variety of activities and has learned to work around her Alpha-1. A lover of woodworking, Isabel "set off a chain of events" breathing the dust it produced by taking her mask off too soon. She still loves to make things, but has learned not to overdo it. Isabel's efforts have won scores of ribbons at state and county fairs for her wood carving, as well as for her embroidery, baking and painted gourd birdhouses.

"I believe in the Lord and when I have a hard job, His strength always sees me through," said Isabel.

Her craftwork has also helped her cope in times of grief, such as the recent tragic death of her beloved grandson, Robert, whom she memorialized with a beautiful hand-carved letter to serve as a lasting tribute.

*(continued inside)*

Around Easter, Isabel made the photo-dolls show above for the nurses, pharmacists and staff at Franklin Square Hospital, where she has her weekly infusions. This project won first place at the State Fair two years ago and "astonished" the nurses, who Isabel says "couldn't believe this old Alpha could do such a thing."





Kurt pictured during a recent triathlon; he recently completed 110 miles at the Rolling River Ride "Century" bike race.

# TRAINING FOR SURVIVAL



Jenny rounds the bend in a recent race.

## Mother of four, Jenny Faull, started training to run her first marathon, while Reverend Kurt Gamlin learned to swim at age 51 to prepare for his first triathlon.

She had initially started a walking program to help build natural painkillers and help her cope with the symptoms of fibromyalgia. Her shortness of breath curtailed her walking program until after her Alpha-1 diagnosis and attendance at an Alpha meeting. The program featured a speaker who had written a study on the benefits of exercise for pulmonary rehab and she decided to start walking again. Her pace improved and she advanced to running, with her kids riding along on their bikes to give her support and encouragement.

An interesting fact, after just three months on her infusion therapy, Jenny's symptoms of fibromyalgia disappeared. Her physicians are not sure why this has occurred, but at 41, Jenny is not going to let up on any of her therapeutic regimens.

Jenny recently had a setback when she tore a cartilage in her knee, but pledges to be back to training in time for the spring races. In the meantime, she philosophically pronounces it "a good day for a walk."

Kurt has always exercised and, after his diagnosis as an Alpha two years ago, has been having infusions, closely monitoring his progress, and gradually building his fitness regimen with slow jogging and now, running.

A Methodist pastor in Wheaton, Illinois, he and his wife have also reared their three children to have a focus on athletics. His current goal of becoming a triathlete (running, biking and swimming) pushed him to take swimming lessons twice a week to learn to swim.

Exercise has always helped Kurt start his day and he feels strongly that "exercise helps mentally as well as physically." "It gets those endorphins going and sharpens the mind," he explains.

### Great Websites for Alphas

AlphaNet .....[www.alphanet.org](http://www.alphanet.org)

Alpha-1 Association.....[www.alpha1.org](http://www.alpha1.org)

Alpha-1 Foundation.....[www.alphaone.org](http://www.alphaone.org)

Alpha-1 Research Registry .....[www.alphaoneregistry.org](http://www.alphaoneregistry.org)

Alpha-1 Testing.....[www.ShortofBreathGetTested.org](http://www.ShortofBreathGetTested.org)

Prolastin® .....[www.prolastin.com](http://www.prolastin.com)

Zemaira® .....[www.zemaira.com](http://www.zemaira.com)

Kamada.....[www.Kamada.com](http://www.Kamada.com)

American Lung Association...[www.lungusa.org](http://www.lungusa.org)

*New Year's Resolution: Start a new exercise program. See the Big Fat Reference Guide™ at [www.alphanet.org](http://www.alphanet.org) for exercise suggestions.*



# AGE IS NO BARRIER FOR THESE ALPHAS *(continued from cover)*

During her weekly infusions, Isabel started crocheting slippers for other patients and the nurses, and getting a great response. "I made Boo-Boo Bunnies with a message inside that always makes my fellow patients laugh," explained Isabel. "Then in about one minute I teach them how to make them for others." She discovered that teaching the other patients how to make crafts opened them up to conversation, helped them unwind, relax and ultimately, feel better.

She describes her latest "prank" as tossing a handful of gourd seeds over the fence to her son's property onto an unplanted plot of land. She's having fun watching the gourds multiply "as they almost double overnight" and wondering what she can do with all those gourds for her next project.

Joyce Martyn knows how to party. The festivities for her 80th birthday turned into a weeklong celebration, involving her family, church, infusion nurses, and friends at her Tucson, Arizona retirement center. Members of her Alpha-1 support group even showed up with a home-baked cake for a special visit.

After a busy career working in hospital admissions, Joyce volunteered as her church secretary for many years. She keeps busy and is on the go, still driving and getting out on her own regularly (with a lift on her car for her scooter).

When asked about how she stays so active and limber, Joyce reports, "determination has a great deal to do with it, I don't just sit back and relax." She enjoys reading and keeps fit with daily exercises, which she now does lying on her bed since walking does tire her.

Still active with her church, Joyce sings in the choir, "breathing when I have to" and enjoys giving the congregation's kids rides on her scooter, an activity that has made her extremely popular.

She was 56 when she was finally diagnosed after 20 years of "doctors getting it wrong." "I thought I had a mental problem because they could never find anything wrong with me," explained Joyce.

She finally asked to be tested when her brother (also an Alpha), told her about a new theory involving a missing protein. Two of her grandsons are Alphas as well. Joyce has a very rare Alpha gene (ZMheerlen) that has been traced back to her Dutch heredity. She is one of a few identified in the U.S. with this specific gene that can be traced back to a small town in the Netherlands.

"The (Alpha-1) Registry has been a blessing, helping my family find out this information," said Joyce.



During her infusion with Head Nurse Janet, Isabel works on her boo boo bunnies and slippers. Each bunny is made to hold ice to help make "boo boos" feel better.



"It was marvelous," said Joyce, as she rides again, this time not on a scooter, but comfortably on the back of a friend's Harley, a pastime she enjoyed many years ago as a teenager.



To the delight of her neighborhood children, Isabel drives her sulky with her miniature horse, Merrileggs.



Joyce pictured with her daughter Lori and grandson Max, who is also an Alpha, after her 80th birthday celebration at church, one of many during her birthday festivities.

*New Year's Resolution:*

*Try something you've always wanted to do!*

## ALPHAS IN THE NEWS

### AN ADVOCATE IS BORN

Richard Fallstich, who was featured in the AlphaNetter, Spring '07, about his double lung/liver transplant, has decided to take on a more activist role to raise awareness of organ donation. An opinion piece, written by Richard about his experience and the importance of organ donation, was recently featured in *The Morning Call*, the leading newspaper serving the Lehigh Valley, PA communities.

### AN ALPHA'S STORY IS CHRONICLED

*The Star Press*, in Muncie, Indiana, is running a series on Alpha, Judi Crouch, who is waiting for a double lung transplant at the Cleveland Clinic. Several other Alphas have logged on to the newspaper's on-line Readers Forum to express support for Judi. Although Judi has hit a few snags, she is now awaiting her transplant and plans to stay in Cleveland, with her 17-year-old son Zach, during her recuperation. To follow Judi's story, log on to [www.thestarpress.com](http://www.thestarpress.com), go to archives and put "Fighting the Good Fight" in the search field (there is a \$2.95 charge to access the full text).

### NEWSPAPER HELPS ALPHA FIND TRANSPLANT DONOR FAMILY

*The Arizona Republic* featured a heart-wrenching transplant

### New Year's Resolution: Attend a Support Group Meeting

story that focused on a family who donated their daughter's liver to a child with liver failure due to Alpha-1. Mary Jo Morris was diagnosed before age 3 and received the transplant at age 10, after her parents were told she had just four weeks to live. Now 33, she wanted to find the family that had made this special gift. For the full story, log on to the [www.azcentral.com/arizonarepublic/news](http://www.azcentral.com/arizonarepublic/news) and type "Mary Jo Morris" in the search field. There you will be able to read all the stories including how *The Arizona Republic* helped her find her donor-family (there are access charges from \$2.50 an article).

### WHERE IN THE WORLD?

Hal Nordwall, and his wife Hope, from Mooresville, NC, appeared in *The Charlotte Observer* in a group photo of their recent trip to Peru. The story of their trip was featured in the Summer '07 AlphaNetter.

### NEW BINGHAMTON, NY SUPPORT GROUP FORMED

The new Binghamton, NY Support Group was recently started by group leader Katherine Arnaldi and AlphaNet Patient Services Coordinator Pat MacInnes. Pat reports everyone enjoyed a "delicious lunch" supplied by Talecris Rep Mitch Ling. Guest speaker Donovan Quill, who works for Centric, spoke about how Alpha-1 has affected his family.

"It was a great meeting for our first time and I was very proud of everyone for coming," said MacInnes. "I was so glad to meet Alphas that I hadn't met before; they are wonderful people."

Regular meetings will be held throughout 2008. For more information call Pat MacInnes toll-free at 1-877-277-7931 or e-mail [pmacinn@alphanet.org](mailto:pmacinn@alphanet.org)

## A Very Special Holiday Gift

AlphaNet CEO Robert C. Barrett has presented the Alpha-1 Foundation with a check for \$60,000. This special check is on behalf of the thousands of Alphas who are part of the AlphaNet family. The contribution is in lieu of the traditional Holiday gift of oranges previously sent to each Alpha participating in AlphaNet's Disease Management and Prevention program (ADMAP).

"It was actually several Alpha-1 patients who told us they would rather have the \$22 cost of their gift directed towards additional research," explained Barrett. "After discussions with AlphaNet Board members and Patient Service Coordinators, it was decided the funds would be better used to support the search for a cure for Alpha-1 Antitrypsin Deficiency."

Alpha-1 Foundation President and CEO John Walsh said, "I am constantly amazed by the generosity from within the Alpha-1 community and am deeply grateful for this unexpected gift."

*Friends of AlphaNet who do wish to have some Florida citrus, may contact Al's Family Farms at (800) 544-3366 or [www.alsfamilyfarms.com](http://www.alsfamilyfarms.com). Al's is offering the same special \$12 discount that he gave AlphaNet off any order. Just provide the code: AN07, when you place an order.*



**Binghamton Support Group:** pictured, front row, from left: Shawn and her mother, Ruth, Katherine Arnaldi, and Lorraine. Back row, from left: Ben, Pat MacInnes, Larry, Rose, Stanley, Watty, Ken, Donovan Quill, and Mitch Ling.

## CLINICAL CORNER

# NURSE EDUCATION PROGRAM FOR ALPHA-1 AND AUGMENTATION THERAPY

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

If you have 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](mailto:tkitchen@alphanet.org) or 877-553-0093.

Two significant issues have compelled AlphaNet to provide education for the medical community specific to Alpha-1. First, there is a general lack of awareness about Alpha-1 in the population at large, as well as among members of the medical community. Clinical research studies have shown that, once a patient with Alpha-1 develops symptoms, it takes an average of seven years and visits to five different doctors before the diagnosis of Alpha-1 is made.

*Are you aware that Alpha-1 is one of the most common serious genetic disorders and it is believed that only 7,000 of the estimated 100,000 Americans with severe Alpha-1 have been diagnosed to date? An additional 20 million Americans are estimated to be genetic carriers of this disorder. Alpha-1 can cause severe liver disease in children or severe liver and lung disease in adults, presenting as cirrhosis or early emphysema.*

Currently, the World Health Organization, the American Thoracic Society, and the European Respiratory Society recommend that all adults with the following conditions be tested for Alpha-1/COPD: chronic bronchitis and emphysema, chronic asthma, unexplained bronchiectasis, family history of Alpha-1 and chronic liver disease.

Equally important is the second issue; the recognition that significant variations in the care and treatment of Alpha-1 exist in the medical community and that these variations may adversely affect the health of individuals with Alpha-1.

### FREE EDUCATION PROGRAMS AVAILABLE FOR MEDICAL PROFESSIONALS

In an effort to address these two issues, AlphaNet provides two professional education programs for the medical community. Each

program is approved for continuing education credits by its respective medical specialty.

One program is for physicians and respiratory therapists and offers Continuing Medical Education (CME) credit for physicians and/or Continuing Respiratory Care Education (CRCE) for respiratory therapists. The program reviews the recently published "Standards for the Diagnosis and Management of Individuals with Alpha-1 Antitrypsin Deficiency."

The other program is for nurses and is approved for 3 contact hours by CNE-Net, an accredited approver by the American Nurse Credentialing Center's Commission on Accreditation. It includes an instructional DVD. The video, along with supplemental written materials, comprises an educational program titled "Alpha-1 Antitrypsin Deficiency and Augmentation Therapy."

### HOW NURSING PROGRAM GOALS BENEFIT ALPHAS:

1. Upon completion of this program the nurse will have a better understanding of the disorder and its treatment.
2. Enhance the care of individuals receiving IV augmentation therapy by providing specific and detailed instructions regarding the drugs preparation and infusion.
3. Provide the nurse and the patients they serve with access to resources in the community for further information and support.

Instructions for this program are included with the accompanying materials. Upon successful completion of the Post Test with a grade of at least 80%, along with the submission of the Registration and Evaluation Forms, each participant will receive a certificate and 3 contact hours.

**AlphaNet provides this program free to all nurses. I encourage you to ask your nurse to become certified as an "Alpha Nurse" by completing this program. If your nurse has not viewed this video and taken the exam, please have them call me at 877-553-0093; I will make sure he or she receives a copy.**

*New Year's Resolution: Tell Your Nurse About  
AlphaNet's Free Education Program*

**NOW AVAILABLE: The Nursing Education Program  
is on the AlphaNet website, [www.alphanet.org](http://www.alphanet.org)**



# Calendars:

## ALPHA-1 FOUNDATION & TEAM ALPHA EVENT CALENDAR

**February** - Yoga Grove's Class for Alpha-1  
Coconut Grove, FL

**February 2** - Race up Boston Place  
Boston, MA

**February 15** - Eaton's Alpha-1 Awareness Across the USA  
St. Augustine, FL

**MAY 2** - Celebration of Life  
Key Largo, FL

**MAY 17** - First Annual Trek for Alpha-1  
East Lyme, CT

**ONGOING** - Alpha-1 Awareness Wristbands.  
Alpha-1 Scarf, Tie & Car Magnet Campaign  
USA & Abroad

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

## ALPHA-1 ASSOCIATION PROGRAMS & ACTIVITIES

### Education Days & Regional Support Group Meetings

**MARCH 9** -  
Alpha-1 Education Day  
Phoenix, AZ

**MARCH 29** -  
Regional Support Group Meeting  
Jackson, MS

**JUNE 20-22**  
Alpha-1 Association National Conference  
St. Louis, MO

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

## SPECIAL TOPIC REFERENCE GUIDES AVAILABLE

New brochures 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.  
Titles include: *Traveling with Alpha-1*, *Oxygen Therapy*, *Understanding Pulmonary Exacerbations* and *Staying Healthy/Management of Environmental Risk Factors*.



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