

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

## AlphaNet Welcomes New COO



**Susan Christian** joined AlphaNet as its first Chief Operating Officer (COO) this past May. She has more than 15 years of experience in pharmaceutical operations and research including project management of teams conducting international clinical research for drugs and medical devices. Susan's range of clinical experience includes work in infectious diseases, oncology, dermatology, hematology and pain management. Of special note, she was part of the Sandoz team that obtained FDA approval of cyclosporine for transplant anti-rejection.

Susan received a bachelor's degree from the University of Pennsylvania and an MBA from Drexel University in Philadelphia. She has recently relocated to Coconut Grove, Florida and is the mother of two grown children.

Clip and Save on your fridge or bulletin board

### NOT TOO EARLY TO THINK ABOUT FLU SHOTS

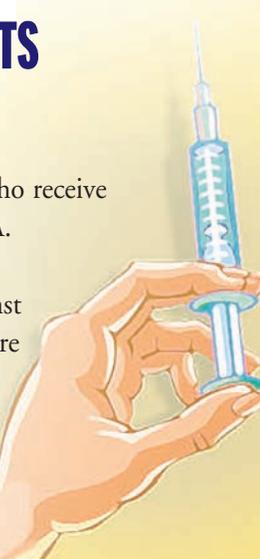
It's not too early to start thinking about getting your flu shot. Supplies are expected to be available during the month of October.

"Our Outcome Study data has shown benefits for individuals who receive regular flu shots," according to AlphaNet Medical Director Robert A. (Sandy) Sandhaus, MD, PhD.

Although having a flu shot will not necessarily protect you against getting bird flu, it does make it less likely that the bird flu will acquire the ability to directly infect humans.

Plan to have your vaccine early in case supplies run low again this year.

Visit [www.alphanet.org](http://www.alphanet.org) for links to important avian influenza websites.



**EMERGENCY  
EVACUATION  
CONTACT**

If you must leave your home due to an emergency evacuation caused by natural disaster, AlphaNet and your AlphaNet Coordinator may be able to help in your time of need.

Please keep your Coordinator informed of your emergency contact information, your temporary new location, and any need you have for changes to delivery of your augmentation therapy or supplies. If your life is disrupted by an emergency situation, rely on us and keep us informed.

# CONTROLLING THE PRIVACY OF YOUR MEDICAL RECORDS

Message from AlphaNet's Privacy Officer and COO, Susan M. Christian



At AlphaNet we want all Alphas to be empowered in their healthcare management. An important part of that empowerment is having access to your medical information.

The insurance industry shares private consumer information. They do this to control costs and prevent fraud through the Massachusetts-based clearinghouse, MIB Group, Inc. This 100-year-old company keeps applicants honest about reporting health information while protecting consumer privacy.

Information is kept in a coded form at MIB, with data about medical conditions shared throughout the industry during insurance application underwriting. MIB does not have the actual insurance application or medical record of any individual. MIB only keeps health information about individuals who have applied for life, health, disability or long-term care insurance during the last seven years.

**You have a right to know what information, if any, the insurance industry keeps about you.  
To request a free copy of your MIB report call 866-692-6901.**

## CATCHING HER BREATH

Illinois Alpha Sherri Clardy, RN, has been playing in a softball league for the last 20 years. Participating since before her Alpha-1 diagnosis, Sherri is currently catcher for the Lindgren, Callahan & VanOsdol team.

"I look forward to it every week," says Sherri. "I don't know what it is about hitting a ball and running around that feels so good, but I love it."



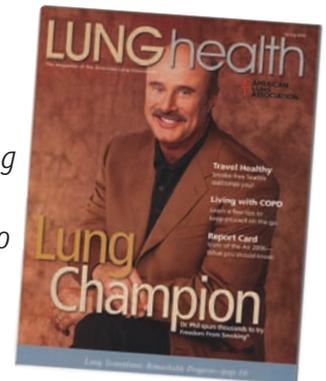
The group of 15+ women ranges in age from the 20s through 40s and play every Thursday evening during the summer months in Winnebago. As the only Alpha on the team, Sherri says they make allowances for her

if she is not breathing as well. She says, "It's all about companionship and camaraderie and we sure do have fun."



## ALPHAS IN THE NEWS

Lung transplant survivors Shirley Dennis and Mary Pierce were featured in the spring issue of Lung Health (page 10) published by the American Lung Association. Their photo was used to illustrate a story explaining many details and improvements about lung transplants as well as the need for organ donors.



## SUPPORT GROUP NEWS

**New Groups Launched in Kentucky, West Virginia, Ohio & North Carolina**

Libby Wilson has begun a new support group in *Lexington, Kentucky* and the new *Tri-State Alphas Support Group*, serving West Virginia, Kentucky and Ohio, is under the direction of new leader, Valerie Guthrie. In Wilmington, North Carolina the new *East Carolina Alphas Support Group* is now under the direction of co-leaders Larry Tipper and Gayle Allison.

The *Kentuckiana Support Group* welcomes new leader, Erika Garloch, who has taken the reins to continue this group after their beloved leader Rosemary Bybee passed away from complications during lung transplant.

Neva Maynor has taken over the leadership of the *West Virginia Alpha-1 Support Group* after former leader Gayle Allison moved to NC and *Northern Virginia* welcomes new support group leader Elsa Anders.

**For information about the support groups above contact Gayle Allison, toll free: 877-982-5742. For info about other support groups contact Cathey Horsak at the Alpha-1 Association, toll free: 877-346-3212.**

# OXYGEN & PULMONARY REHAB CAN IMPROVE YOUR LIFE

## *Breathing easier is a top priority for many Alphas*

and good pulmonary rehab can make a life-altering difference. The use of oxygen is also a lifeline for many, but some Alphas don't use their oxygen as effectively as they could. Studies show that if you need supplemental oxygen while at rest, you will have a better chance to live longer if you use it at least 16 hours a day. Some sacrifice the use of oxygen due to issues of self-image. But today many of the rules are changing. Oxygen delivery systems get easier, smaller and more portable every year. Today you can even have oxygen delivered through Oxy-View eyewear or easily conceal your supply in a child's backpack or a purse with a detachable strap. And you can reduce your dependency on oxygen with good pulmonary rehab.

### **Sharon Workman from Crossville, Tennessee would like to share the difference Pulmonary Rehabilitation has made in her daily life.**

*"I was diagnosed with Alpha-1 in 1996. Over the next six years, it seems I had one respiratory infection after another and my shortness of breath became much more pronounced. As a result, I'm afraid my underlying solution was to limit, whenever possible, any activities that made me short of breath.*

By 2004, my blood/oxygen saturation level had declined to a point at which my doctor prescribed the use of 24-hour/ 7-day-a-week supplemental oxygen. Over the next year, I participated in studies associated with the development of the "Big Fat Reference Guide" for Alphas, and had many discussions with my AlphaNet Coordinator regarding the section addressing pulmonary rehabilitation. I purchased a treadmill and began walking a mile per day. Although I began to have more energy, I continued to have frequent respiratory infections and frequent shortness of breath.

In July 2005, after a particularly poor pulmonary function test, I asked my doctor if he could refer me to a pulmonary rehab program as close to my home as possible. The closest program was 40 miles away, but I felt I had to try something different.

I began the pulmonary rehab program, which lasted for 12 weeks, meeting twice a week for 1 hour. The respiratory therapist in charge was very familiar with Alpha-1 and took considerable time to accurately understand my current level of health, lung function, and oxygen requirements. *In an effort to make more efficient use of the*

*current lung function I had, he outlined an exercise program to strengthen both my upper and lower body, and provided me with two breathing "exercisers" designed to strengthen specific muscles that aid in moving air into and out of the lungs.* My exercises, and the time and order in which I completed them, were selected to provide a minimum of shortness of breath and fatigue during any one session. He also taught me exercises to do at home when the course was completed.

*Since beginning my pulmonary exercises almost a year ago, I have been sleeping better, experienced only one minor respiratory infection, and have increased my energy, stamina, and upper body strength* to the point at which my daily tasks and errands no longer completely exhaust me. When I do become short of breath, I am able to take deeper breaths, which helps me relax and recover more quickly. The most noticeable change has been the improvement in my blood/oxygen saturation level. I can now complete my exercises, as well as many of my daily tasks and errands, without the use of supplemental oxygen. I continue to use my oxygen at night, and as necessary on some of the more hot and humid days we have here in the South. To have reclaimed some of the freedom to move about during the day without the added restrictions of supplemental oxygen, even temporarily, is more than enough reward for the hard work. I sincerely hope the benefits I have realized will encourage other Alphas to give pulmonary rehabilitation a try."

To find a pulmonary rehab program in your area:  
[www.aacvpr.org/resources/search\\_program.cfm](http://www.aacvpr.org/resources/search_program.cfm)

For good information about pulmonary issues, tips, etc.:  
[www.pulmonarypaper.org](http://www.pulmonarypaper.org)

# When you look at me

by Willis Landrum, Alpha from Somerset, TX

*When you look at me, what do you see?  
Just a person in a wheel chair?  
An oxygen hose and tank?  
A faraway look, a blank face and eyes?  
Is that what you see when you look at me?*

*Hello, I'm a man who sees and thinks.  
A man who dreamed and felt great things.  
I know now that's not what it seems.  
But feeling I still have, to see the pity you display.  
I want not your pitiful efforts to placate me.*

*Before my illness, I was just like you,  
Full of life, joy and dreams, children played at my feet.  
A father and a husband, a job and things to do.  
I didn't ask for this to happen, but it did.  
When you look at me, see yourself, it could happen.*

*Bitterness has no place in my heart, only Christ.  
My strength when I am weak, my power in that name.  
He has taught me how to love, forgiveness in Him I seek.  
You may not see that in me now, but my friend look deep.  
There will come a day, maybe sooner than you think.*

*When you look at me what do you see?  
Not a defeated person, nor proud and haughty.  
I'm not better than you, or you better than me.  
Ask me my name. How I might be, but don't  
look though me and pass me by. I am still human.*

*There are many just like me, who want a human smile.  
A cheerful conversation, a kindly how are you.  
When you, who are healthy, see someone like me.  
Think before passing judgment, then look away.  
Think, it could just as well be you, sitting in this chair.*

## CLINICAL CORNER

***This regular feature will highlight issues relating to infusion therapy and procedures, IV devices, proper techniques, infection control and more. AlphaNet's Clinical Nurse Manager, Kathy McKay, RN, will answer your questions in future issues (or anytime you call). If you have a clinical topic you think all Alphas should learn about in the next issue of AlphaNetter, please contact Kathy at [kmckay@alphanet.org](mailto:kmckay@alphanet.org) or 877-913-8141.***

## TIPS FOR INFUSION SUPPLIES

- ✓ Reconcile supplies delivered against the packing list
- ✓ Be sure the items received are items you are currently using and in the correct quantities
- ✓ Be sure you know what the items are and how they are to be used
- ✓ Keep an accurate inventory of items on hand
- ✓ Always keep a few extra items for back-up and notify your AlphaNet Coordinator for replacements should you use these back-up supplies
- ✓ Know when the next supply ordering period will be and when the next delivery is scheduled for
- ✓ Understand the recommendation for single use of flush solutions such as sodium chloride or heparin. Even though these vials may indicate by labeling or volume they are "multi-dose", they are to be used for only one infusion to maintain good infection control practices. Clinical studies have indicated that multiple use of the vials increases the risk of infection. The cost savings are negligible, when you consider the cost and resources required to treat an infection.
- ✓ Know where to seek help or have your questions answered. Your AlphaNet Coordinator is available to assist you with keeping your supplies in order and your inventory up-to-date. And your AlphaNet clinical nurse is always ready to help you work through any issue regarding your infusion needs. We are also happy to interact with your local nursing support team as needed or requested.



## NEW VIDEOS AVAILABLE

AlphaNet has two new videos.

**Healthy Connections** is a 6:30 minute piece that explains AlphaNet and its role in serving Alphas. A number of AlphaNet Coordinators and Alphas are in the video, which was filmed throughout the US.

**Alpha-1 01: Questions & Answers** is 18 minutes and features

AlphaNet Medical Director Robert A. (Sandy) Sandhaus, MD, PhD explaining Alpha-1 Antitrypsin Deficiency, its diagnosis and treatment.

*To request a VHD or DVD copy call AlphaNet at 800-577-2638 x247*

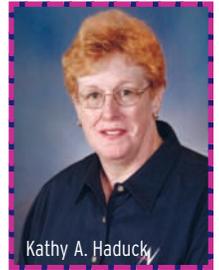
# CONGRATULATIONS

## KATHY HADUCK & GAYLE ALLISON RECEIVE ALPHANET HONORS

Nothing characterizes AlphaNet more than the services provided to Alphas by AlphaNet Coordinators. While each of the 21 AlphaNet Coordinators provides specialized, caring support to the Alphas in their network, AlphaNet annually acknowledges the contributions of those whose service is exceptional.

This year's AlphaNet Award for Exceptional Service was presented to Coordinator, Kathleen (Kathy) Haduck. The award recognizes extraordinary effort to further AlphaNet's mission. Kathy has built strong bonds with her Alphas, has consistently high performance measures, and obtains high positive feedback from the community she serves. Her Alpha-clients know this is more than a job to Kathy.

The AlphaNet Nancy C. Ferguson Award for Excellence in Service to the Alpha-1 community was presented to Coordinator, Gayle Allison. Gayle's impact goes beyond supporting her assigned AlphaNet clients, to include organizing the July 8th Celebration of Life Dinner Cruise which raised over \$20,000 for the Alpha-1 Foundation, establishing four new Alpha-1 Association support group meetings and serving as an Alpha-1 Association leader. This is the second time Gayle has received this distinction.



Kathy A. Haduck



Gayle L. Allison

*Thanks to Kathy, Gayle and all the AlphaNet Coordinators for their special dedication to Alphas.*

## PROBLEMS SOLVED: ALPHAS ADVOCATE

*People with health issues need to become their own advocate and enlist the support of their family as assistant advocates. At AlphaNet we advocate for Alphas in general with the medical, insurance and legislative communities; but nothing can take the place of Alphas standing up for their own rights.*

### CLASS ACTION

Mary Daugherty, an Alpha from Vincennes, Indiana took on the State of Indiana to keep her Medicaid disability benefits.

When 10,000 Indiana residents lost benefits after being wrongly kicked out of the State's Medicaid program by the Family and Social Service Administration, Mary, who had a double lung-transplant in 2003, became lead plaintiff of a successful class-action lawsuit to have the benefits reinstated. After admission to the hospital in March, Mary found out she no longer had coverage for the necessary drugs to help her body fight rejection of her new lungs. She was also able to get her benefits re-started before the settlement. Before becoming disabled, Mary worked in Medicaid and Medicare billing and was far better informed than most.

Today, Mary continues to use her knowledge to help others understand they have many options for assistance.

### POLITICAL ACTION SAVES THE DAY

When Alpha Ruth Johns, from Shell Knob, Missouri, found Medicare hadn't reimbursed her healthcare provider for her infusions for eight months, she needed to take action. The clinic manager suggested she contact one of her US Senators for a Medicare Advocate. Ruth contacted one US Senator and got no response. She had more luck at the second senator's office, when a staff member listened to her situation and connected her with a Medicare Advocate. Within days she had signed necessary permission forms and received a copy of a letter from Senator Jim Talent's office to the Regional Medicare office in Kansas City requesting quick action for payment. The provider received funds within a week and the problem was solved.

# EVERYONE IS WINNER AT 2006 TRANSPLANT GAMES

Louisville, Kentucky hosted the 2006 US Transplant Games this past June. Randy Harwell's widow, Karen, honored his memory by hosting Alphas, friends, family and members of the Louisville Organ Transplant Support Group during the games. Randy was an AlphaNet Coordinator who passed away in February. He was well known in the area for his work to promote organ donation awareness. He loved the Transplant Games and had been very excited they were going to be held in his hometown of Louisville. Team Alpha provided travel grants to Alpha-athletes and Talecris sponsored a picnic during the games.



Team Alpha liver transplant recipients:  
(l-r) Leigh Cropper, Glen Buzitsky, Bob James,  
Pam Hawver, David Ballinger and Ron Hargarten

## Team Alpha & Medal Winners:

David Ballinger .....Team Illinois  
Henry Eckert .....Team Wisconsin  
Ronald Hargarten .....Team Illinois  
Pam Hawver .....Team South Carolina  
Jerry Killens .....Team Northwest  
Debbie LaBud .....Team Florida  
Glen Buzitsky .....Team Minnesota

Theresa Snyder,  
Team Michigan: .....GOLD, singles bowling  
SILVER, golf  
SILVER, doubles bowling

Mary Pierce, Team Michigan: .....GOLD, racquetball  
Bob James, Team Florida: .....SILVER, singles bowling  
Darrell Nall, Team Illinois: .....SILVER, high jump  
Leigh Cropper, Team Utah: .....BRONZE, racquetball

Team Alpha is sponsored by Talecris Biotherapeutics.

*Congratulations  
All!*

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



Ken Walkley from Michigan is ready to roll.

GET  
MOVING  
WITH  
**TEAM  
ALPHA**

## SEPTEMBER 30

Asthma Walk/ American Lung Assoc.  
Byrd Park - Richmond, VA

## OCTOBER 1

Asthma Walks- McDonald's Hamburger University  
Oak Brook, IL  
Peg Bond Center - Batavia, IL

## OCTOBER 7

Lincoln Home national Historical Site- Springfield, IL

## OCTOBER 14

Liver Walk/American Liver Foundation  
Oakbrook, IL

## ALPHA-1 EDUCATION DAYS

September 16 – University of Florida, Gainesville, FL  
November 11 – Oakbrook, IL

## COPD EDUCATION DAYS

October 14 – Medical University of  
South Carolina, Charleston, SC  
October 25 – Florida, Ormond Beach, FL  
November 4 – Brigham & Women's Hospital,  
Boston, MA

  
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