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# The AlphaNetter

The AlphaNetter is a publication of AlphaNet, Inc.

## MAJOR MILESTONE REACHED – \$20 MILLION TO ADVANCE ALPHA-1 RESEARCH

AlphaNet recently memorialized \$20 million of donations to the Alpha-1 Foundation. The presentation of an oversized check by AlphaNet CEO Robert C. Barrett to John W. Walsh, President and CEO of the Alpha-1 Foundation, symbolized the significant milestone. Donations have been made throughout the past 10 years.

"The Alpha-1 Foundation is very grateful for the enormous generosity of AlphaNet," said Walsh. "The contributions received from AlphaNet have helped establish the DNA & Tissue Bank, the Alpha-1 Research Registry, and have funded numerous research grants and support programs. The Foundation and the Alpha-1 community recognize AlphaNet's role in the improvement of quality of lives for our fellow Alphas and our search for a cure."

Barrett noted that since its inception, AlphaNet has consistently supported the Alpha-1 Foundation with funding for research efforts and specialized programs benefiting the Alpha-1 community. AlphaNet plans to continue making contributions to the Foundation.

"We are very proud to have been able to contribute our excess revenue to support the Foundation's important research grants and programs," explained Barrett. "AlphaNet's Board members, Patient Services Coordinators, medical and office staffs are celebrating our success in reaching



**A Big Check for Alpha-1.** During the AlphaNet annual meeting this past June, AlphaNet presented a symbolic check for \$20 million to the Alpha-1 Foundation.

Pictured from left to right are John W. Walsh, President and CEO of the Alpha-1 Foundation, and Robert C. Barrett, CEO of AlphaNet.

the \$20 million level of giving to the Alpha-1 Foundation. This contribution would not have been possible without the participation of Alphas in our health management program," said Barrett.

AlphaNet realizes revenues through the provision of health management services to Alphas, clinical trial management activities and other specialized services. AlphaNet donates funds to the Alpha-1 Foundation and other organizations within the Alpha-1 community. AlphaNet is the Alpha-1 Foundation's largest contributor.

The Alpha-1 Foundation is dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency. If you would like to make a donation, please call 1-877-2-CURE-A1.

# ALPHAS

*“I see evidence every day that Alphas who take charge of their lives, will feel better and live longer.”*

*Robert A. Sandhaus, MD,  
Medical Director, AlphaNet*

Alphas across the country are finding a variety of ways to take charge and remain in control of their destinies.

Jim Murdock makes and plays Native American-style flutes to build his lung strength. Volunteering for Habitat for Humanity, Texas residents Andy Carle and his wife Michelle, have earned their own new home with labors of love and hard work.

Tammy Presley has overcome many of life's roadblocks with determination and a positive attitude.

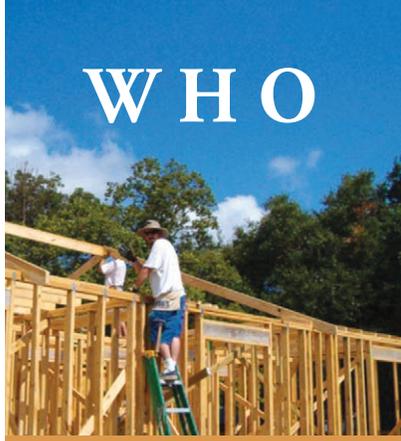
## **A BREATH OF FRESH AIR**

After a nurse told him he needed to do something to exercise his lungs, Jim bought a few Native American flute albums. Liking what he heard, he bought two flutes and then taught himself how to make copies. His first effort took six months, his second two days.

Jim loves to play the flutes and has expanded his repertoire to include other types of flutes from Japan and Peru as well as harmonica. Generally, he plays for about 20 minutes at a time and, in addition to daily half hour walks, he reports it has really helped his lungs. Now, his nine grandkids all want flutes, so they can play along. And, if that is not rewarding enough, Jim has 15 orders for his hand-crafted flutes. Jim reports that every time he plays one of his flutes or shows them off, more people want him to make them one.

Still working for the Utah Department of Transportation, Jim, who lives in Kanarrville, used to enjoy classic car repair, but was not able to continue that activity. His new hobby gives him hours of enjoyment, a new business venture, and helps him feel better.

# WHO



**Working for Habitat for Humanity, Andy climbs a ladder to help with the roof.**



**Jim makes beautiful music with one of his many flutes.**



**Devoted grandmother Tammy with newly born grandson Ethan.**

# INSPIRE

## **ONE NAIL AT A TIME**

Even though he can no longer work or enjoy the hobbies he used to have, Andy does what he can to be productive. He and his wife have helped build three other Habitat for Humanity houses, putting in close to 800 hours of service. This past August they moved into their own Habitat house with the pride that comes from helping build it.

“I can't imagine not helping other people have the opportunity to be in their own house,” Andy said. “It's pretty exciting. At each dedication, I get teary-eyed like everyone else.”

## **GET SOME ATTITUDE**

East Tennessean Tammy has experienced a lifetime of tragedies and hardships during her life, but through it all is a positive force in her family and among those who know her.

Tammy explains it all has to do with attitude. Diagnosed with Alpha-1 at 25, Tammy decided she had two choices about her life with Alpha-1 “to live in it or live with it” and she chose to live with it.

Her daddy taught her “no matter where you are and what your education is, no one can stop you from reading” and so she read all she could about Alpha-1 and her condition. Today, she uses household chores to help her exercise, often carrying five gallon buckets of water 200 yards to water a field, or chopping wood to burn for heat, with a mask, of course. Learning to work around her infusions and her bad days, Tammy says that any morning you wake up, get out of bed and get your clothes on is good – you have done something positive for that day.

Feeling that when one door closes another opens, her medical team helped her enroll for disability after the loss of her job and her new husband is “very special” and a wonderful caregiver.

“I actually feel blessed to have this disease,” said Tammy, “because I know what I have and how to deal with it. I plan to see my kids and grandkids grow up.”

## Two New Coordinators Join the AlphaNet Family

This past June, **Jodi Roth, RN** and **Jim Quill** joined the ranks of AlphaNet Patient Services Coordinators.

Jodi will cover Minnesota and Wisconsin from her home base in Harvard, Illinois. Professionally, Jodi has more than 30 years of healthcare experience, having worked in both hospital and clinic settings. She fulfilled her childhood dream of becoming a Registered Nurse in 1998. With a lung capacity of 23 percent, Jodi retired two years ago to devote herself to pulmonary rehab and focus on improving her health.

As Coordinator-at-Large, Jim Quill will work with Alphas throughout the country when their Coordinator is on leave, vacation or not available. Jim received a bi-lateral lung transplant in 2006, and retired after 34 years in the public school system as a teacher and principal. His home is in Levittown, Pennsylvania.

AlphaNet has trained both Jodi and Jim in health management, support systems and facilitation of infusion supplies. They both look forward to meeting, educating and counseling other Alphas.



JODI ROTH



JIM QUILL

## AlphaNet Welcomes New Nurse, Teresa A. Kitchen, BSN, RN

**Teresa Kitchen, RN**, joined AlphaNet this past summer as Clinical Nurse Manager. She received her BSN in 1993, from Southern Illinois University at Edwardsville. Teresa has an extensive background in both home infusion and oncology and has spent six of her 14 years as a RN working with AlphaNet and the Alpha-1 community. She lives in Edwardsville, Illinois with her husband and two sons.

Patients, nurses and physicians are encouraged to contact Teresa at (888) 553-0093 or [tkitchen@alphanet.org](mailto:tkitchen@alphanet.org)



TERESA KITCHEN

## Judy Rose and Sandy Singleton Honored at Annual Meeting

Each year AlphaNet acknowledges the contributions of those whose service is

exceptional. During the recent annual meeting, special recognition was given to two exceptional AlphaNet Patient Services Coordinators.

**Judy Rose** was presented with the AlphaNet Coordinator of the Year Award in recognition of her extraordinary service to the Alpha community. While covering for fellow Coordinators during their extended leaves of absence as well as for sick or traveling coworkers, Judy continued to serve her own Alphas throughout Arizona and New Mexico. Incredibly, she maintained her busy workload and extra coverage in spite of her own poor health, meeting all AlphaNet standards.

This year's Nancy C. Ferguson Award was presented to Coordinator, **Sandy Singleton**. The award recognizes excellence in service to the Alpha-1 community. On a daily basis, Sandy demonstrated her enthusiasm within the community by often making extended road trips to see her Alphas. Scheduling her trips around support group meetings, Sandy also visited Alphas confined to nursing homes. Throughout her travels, she never missed a beat, continuing to receive and make her scheduled calls within her Alpha-network.



SANDY L. SINGLETON

## Additional Honors Go To...

The Alpha-1 Association honored several in the AlphaNet family at their annual conference this summer. **Patti Brown**, AlphaNet's Texas Coordinator, was recently honored with the 2007 Helen B. Chase Walsh Memorial Award. Each year the Walsh family presents this award at the Alpha-1 Association's National Conference to someone who embodies the spirit and courage demonstrated by Helen Chase Walsh and her struggle with Alpha-1.

For notable service to the Alpha-1 community **Darrell Nall** received a Special Appreciation Award for his significant contribution and dedication handling the oxygen needs of Alphas at the Associations' national conferences.

**Dr. Robert "Sandy" Sandhaus** received the Physician Appreciation Award for many years of clinical care, research and volunteer service. And, for her years of nurturing support and loyal dedication, the Excellence in Nursing Award was presented to **Kathleen McKay, R.N.**



JUDY K. ROSE

## An important aspect of self-care for all Alphas is to reduce the risk of acquiring an infection, especially a lung infection.

Almost all devices used to deliver oxygen and inhaled medications become moist from contact with the secretions of breathing and coughing. This moistness creates terrific breeding grounds for bacteria and viruses. It becomes extremely important, therefore, to clean, disinfect and maintain your respiratory equipment in order to significantly reduce the risk of lung infection.

In most cases, the oxygen supply company that provides your oxygen therapy equipment will provide you with instructions on the care and maintenance of your specific equipment. Instructions on cleaning your prescribed inhaler are typically found on the manufacturer's package insert and are the best resource for specific product information.

Presented below are some general tips for cleaning and caring for your respiratory equipment.

### NEBULIZERS

- Wash the nebulizer cup and mouthpiece or facemask in warm soapy water daily (a mild dishwashing liquid works well).
- Rinse the soap completely off the equipment and place it on a clean paper towel to air dry.
- At least 1-2 times weekly (more often if necessary), disinfect your nebulizer cup and mouthpiece or mask. Soak it for 30 minutes in a vinegar/water solution (1 part white vinegar to 3 parts water) in the disinfectant solution your equipment supplier recommends.
- Some nebulizer cups can be placed in the top rack of the dishwasher for disinfection. Ask your supplier.
- Always unplug the unit prior to cleaning the compressor. The compressor should be wiped clean each week or more frequently when visibly soiled.
- Change at frequent intervals. Recommendations vary from every 2-3 weeks to every 6 months. Check with the manufacturer of your particular nebulizer.

### INHALERS

#### Metered Dose Inhaler (MDI)

- Remove the metal canister from the mouthpiece sleeve.
- Wash the mouthpiece sleeve with warm soapy water at least weekly.
- Rinse it with warm water and air dry it thoroughly before reusing.
- Do not submerge or wash the metal canister since water may damage the valve system.

#### Dry Power Inhalers (DPI)

- Clean the mouthpiece at least once a week using a dry cloth.
- Do not wash your dry powder inhaler.
- Make sure to thoroughly wipe away any particles of powder that have collected on the mouthpiece.

### OXYGEN EQUIPMENT

#### Nasal Cannula

- Wipe your cannula with a clean damp cloth daily.
- Wash your nasal cannula with soap and water twice a week.

- There is no need to wash oxygen tubing.
- Replace your nasal cannula and tubing once a month or more often if needed. If you've had a cold or other respiratory infection, replace your cannula after all symptoms are gone.

### OXYGEN MASK

- Clean the mask with soap and warm water daily.
- Replace the mask once every 2-4 weeks or more often if needed, especially if you've had a cold or infection. If you've had a cold or other respiratory infection, replace the facemask after the symptoms are gone.

### HUMIDIFIER (BUBBLER BOTTLE)

- Empty and refill the humidifier bottle with fresh water at least once a day.
- Wash the bottle daily in warm soapy water and rinse well.
- Disinfect the bottle after washing at least every three days by soaking the bottle in a vinegar solution (1 part white vinegar to 3 parts water) for 30 minutes.
- Rinse and shake off excess water (do not towel dry).

## CLINICAL CORNER

### REDUCING YOUR RISK FOR INFECTION: TIPS FOR CLEANING AND DISINFECTING YOUR RESPIRATORY EQUIPMENT

Bonnie Boyd, RN, BS, Director of Disease Management and Clinical

- Refill the bottle until it is half full or less with distilled water
- Do not use tap water. There are minerals and other impurities in tap water that could damage your equipment.
- Replace the bottle along with the tubing and cannula monthly or more often if needed.

### OXYGEN CONCENTRATORS

- Always unplug the unit prior to cleaning.
- Wipe down the unit with a damp cloth and dry it daily.
- The air filter is typically cleaned once or twice a week with warm soapy water.
- Make sure to air dry the air filter thoroughly before placing it back onto the concentrator.
- Always follow the specific instructions from your home medical equipment company for cleaning the compressor filter.
- If you use a Humidifier (Bubbler Bottle), check with the supplier about their recommended method of cleaning the bottle or consider the method outlined above.

## CPAP

- Clean the mask cushion daily with warm, soapy water and allow it to air dry. Use mild dish soap.
- Disinfect the facemask every 3 days by soaking the mask for 30 minutes in a vinegar/water solution or as recommended.
- Hand wash the headgear in mild fabric detergent if soiled and allow it to air dry.
- Empty the humidifier bottle daily and refill it with distilled water.
- Wash the humidifier bottle daily with warm soapy water and allow to air dry.
- Every 3 days disinfect the humidifier bottle following the method recommended by the supplier or as outlined above for "Humidifier".

## ABOUT TRANSTRACHAEL OXYGEN

■ Transtrachael oxygen is given through a small flexible plastic catheter. It is put directly into the trachea (windpipe) through an opening in the neck. A necklace holds the catheter in place. Specific instructions for cleaning your transtrachael catheter and surrounding area should always be provided at the time the system is inserted. Discuss with your healthcare provider any special requirements for cleaning and disinfecting external oxygen equipment such as oxygen tubing, cannulas etc. In general, the care of external oxygen equipment can be done using the same tips discussed above.

Even with proper cleaning, materials in masks, tubing, cannulas, humidifiers and nebulizers, etc., will break down with normal use, resulting in equipment that may not function properly. As these items may be somewhat difficult or inconvenient to disinfect, some respiratory practitioners suggest that it may be easier and even cheaper to replace them

at frequent intervals rather than spend the time and effort required to disinfect them. Be sure to discuss this issue with your oxygen supplier to make an informed decision.

### BEST TIP!

**The most important thing you can do to reduce your risk of infection is.....  
wash your hands!  
Always wash your hands before and after all activities associated with maintaining your oxygen equipment.**

Thanks to the Alpha-1 Education Conference I attended in Alexandria, VA, I felt compelled to write a bit of poetry about the conference. As an Alpha, Alpha-1 support group leader for Western Pennsylvania, a retired RN and a poet, I hope that I am speaking for all the Alphas who attended.

*By Cathy Gould*

*It was near our nation's capital  
Where we all came to meet  
All were anxious to see each other  
It was going to be such a treat*

*Alpha's throughout the land  
Were going to set their sights  
On what our future was going to be  
And to learn about our rights*

*A general session was held  
To address challenges and goals  
So that support group leaders  
Could all express their roles*

*We were taught about body and mind  
And how to decrease stress  
Now we know how to react  
To relieve any kind of duress*

*We learned of the research being done  
All the caring and concern  
Alpha-1's listened intently  
Always willing to know and learn*

*We heard of how the liver and lungs  
Were affected by this syndrome  
How we must always take control  
Of our diet, our life and our home*

*Oxygen therapy, transplants and rehab  
Were some points of the day  
There were so many wonderful themes  
That will help an Alpha in every way*

*Tears were shed for those we lost  
As all their names were told  
We were brought closer in our sorrow  
In our hearts, their lives, we will hold*

*We laughed, we cried, we shared  
Supporting each other with every thought  
It was a memorable time in our lives  
A time that could never be bought*

*So we want to thank all of you  
Who supported this monumental task  
Who worked so hard to bring us together  
There was nothing more we could ask*

*You filled our bodies with delicious morsels  
You addressed our every need  
We will all move forward together  
For a cure we will succeed.*



# Calendars:

## TEAM ALPHA

### Hike for Lung Health 2007 September 23

Join Team Alpha, and founder Mary Pierce, to create awareness of Alpha-1 and work towards the goal of raising \$200,000 to support lung disease education and research in Illinois.

10am - Montrose Harbor, Chicago, IL  
Deer Grove Forest Preserve, Palatine, IL

This is not a race; you can walk 1 mile or 3 miles. To register or get more information, contact Liz Veronda: lveronda@alphanet.org  
888-723-9487

**SEPTEMBER 14-16**  
**23rd Annual Autumn Escape Bike Trek**  
American Lung Association  
Cape Cod, MA

**SEPTEMBER 15**  
**Walk for Life and Breath**  
Charleston, WV

**SEPTEMBER 15-17**  
**25th Annual Trek Tri-Island Cycling Adventure**  
Puget Sound, Edmonds, WA

**SEPTEMBER 29**  
**Walk for Life and Breath.**  
Martinsburg, WV

**OCTOBER 6**  
**Walk for Life and Breath**  
American Lung Association.  
Putnam County, WV

**OCTOBER 6-7**  
**Bizz Johnson Marathon**  
Westwood-Susanville, CA

**OCTOBER 13**  
**Ford Ironman World Championship**  
Kona, Hawaii

## Alpha-1 Education Days & Regional Support Group Meetings

**OCTOBER 27**  
St. Luke's-Roosevelt Hospital, Columbia University  
Medical Center of the New York  
Presbyterian Hospital  
**Regional Support Group**  
New York, NY

**NOVEMBER 19**  
Brigham & Women's Hospital  
**COPD/Alpha-1 Education Day**  
Boston, MA

**DECEMBER 1**  
University of Florida  
**Regional Support Group**  
Orlando, FL

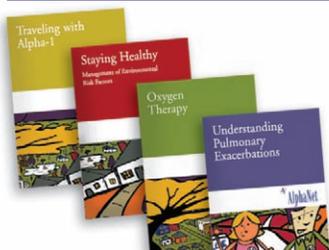
*To find out more about conferences and support groups, visit the Alpha-1 Association website at [www.alpha1.org](http://www.alpha1.org) or call 1-800-521-3025.*

*For Team Alpha information, contact Mary Pierce at 888-883-2991. [mpierce@alphanet.org](mailto:mpierce@alphanet.org)*

## SPECIAL TOPIC REFERENCE GUIDES AVAILABLE

New brochures offer focused information on single topics and have included and expanded on the material in the Big Fat Reference Guide.

For copies, call AlphaNet at 1-800-577-2638, 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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