



FALL 2009

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

**COORDINATORS:**

**Roger R. Bray** 877-227-7914  
rbray@alphanet.org (KY, IN)  
**Patti A. Brown** 877-264-7470  
pbrown@alphanet.org (TX)  
**Victoria (Wicki) S. Cameron** 888-526-9077  
vcameron@alphanet.org (ME, NH, VT, Volunteer)  
**Dan J. Clark** 888-225-9012  
dclark@alphanet.org (MI)  
**Jennifer (Jenny) L. Faulk** 866-697-8530  
jfaulk@alphanet.org (Zemaira, Eastern USA)  
**Kathleen (Kathy) A. Haduck** 800-813-4494  
khaduck@alphanet.org (DE, PA)  
**Marianne K. Mullen** 866-940-3411  
mmullen@alphanet.org (At Large)  
**Patricia (Pat) E. MacInnes** 877-277-7931  
pmacinn@alphanet.org (NY, NJ)  
**Diana J. Patterson** 888-399-0443  
dpatterson@alphanet.org (FL, PR, USVI)  
**Barbara J. Pusey** 800-745-3004  
bpusey@alphanet.org (Zemaira, Western USA)  
**James (Jim) A. Quill** 888-795-6393  
jqull@alphanet.org (At Large)  
**Jim A. Rapp** 866-848-8079  
jrapp@alphanet.org (At Large)  
**Judy K. Rose** 877-860-8694  
jrose@alphanet.org (AZ, ID, MT, NM, UT, WY)  
**Jodi G. Roth** 877-662-4774  
jroth@alphanet.org (MN, WI)  
**Sandy L. Singleton** 877-898-8630  
ssingleton@alphanet.org (CA, HI, AK)  
**Kathleen (Kathie) D. Sivesind** 866-244-1026  
ksivesind@alphanet.org (NV, WA, OR)  
**Sue K. Smith** 888-883-2991  
ssmith@alphanet.org (OH, WV)  
**Kay Swift** 877-742-9078  
kswift@alphanet.org (NE, ND, SD, CO)  
**Gayle Allison Tipper** 877-982-5742  
gallison@alphanet.org (NC, VA, DC)  
**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)

**STAFF:**

**Robert C. Barrett**, Chief Executive Officer  
800-577-2638 ext. 229 rcbarr@alphanet.org  
**Robert A. "Sandy" Sandhaus, MD, PhD, FCCP**  
Medical Director, Executive VP  
800-577-2638 ext. 226 rsandhaus@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  
**Melissa B. 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  
**Rebecca E. Lilian**, Communications Specialist  
800-577-2638 ext. 318 rlilian@alphanet.org  
**Lindsey N. Griffin**, Executive Assistant  
800-577-2638 ext. 243 lgriffin@alphanet.org

# The AlphaNetter



The AlphaNetter is a publication of AlphaNet, Inc.

## Patricia Tew Joins AlphaNet Team

In October, Patty Tew joined AlphaNet as a Patient Service Coordinator-at-large and will work with Alphas throughout the country when their Coordinators are on leave or vacation.

Patty brings with her 22 years of accounting experience in a family-run municipal bond business. She is a Florida native and has been an Orlando support group leader since she helped start the group in 2007. She has also been a member of the Alpha-1 Association Support Group Advisory Committee.



“Once I was comfortable as an Alpha in my own skin,” Patty says, “I knew I wanted to serve and connect with other Alphas. The support group was a way to offer that on a local level. I am excited for this opportunity to provide direct support to my fellow Alphas.”

AlphaNet has trained Patty in health management, support systems and facilitation of infusion supplies. She looks forward to meeting, educating and counseling other Alphas.



## Step Forward Study Steps Up

AlphaNet’s newest clinical research project, known as The Step Forward Study, has kicked off. The study, funded entirely by AlphaNet, is designed to evaluate the effects of interventions and incentives that will increase the activity and fitness of Alphas. Although the study duration is 5 years, the excitement about participating in this study ensured that all 500 study participants were enrolled in just over two months. The study participants are divided into groups, each receiving different approaches.

During the first month of the study, participants began learning the techniques necessary to monitor their activity and health status. Each participant received a personalized spirometer specifically designed for the Step Forward Study. Subsequently, a pedometer and daily diary have been issued to all participants. Participants have the opportunity to use either AlphaNet’s unique internet-based daily diary or a paper version. The internet-based daily diary allows participants to record diary information electronically, allows the study participants and their AlphaNet Coordinators to discuss progress on a continuous basis, and will soon allow viewing of tables and graphs showing ongoing progress.

The Step Forward Study is off to a great start with much much more to come! Stay tuned for future updates. If you would like to “Step Forward”, you can still be placed on the waiting list. Contact Rebecca Lilian at 800-577-2638 ext. 318 to inquire.

H1N1 Medical Advisory Inside





## Retired Chef Keeps on Cooking

After 50 years in the food industry, retired, professional chef, Michael Swain, is still putting his food-sense to good use. Michael started out washing dishes at a seafood house in New Hampshire, worked his way to fry cook and just kept cooking. He joined the Navy in 1963, where he attended Cooks and Bakers school, and served until 1966. He has worked in restaurants, institutions and spent most of his career as a corporate chef.

Michael's Alpha-1 caused him to retire from corporate food service in 2000, but that hasn't kept him out of the kitchen. He still cooks the family meal, hosts holiday gatherings and regularly sends his son a recipe-of-the-month.

"I send him a recipe from the vault every month, sometimes more. It keeps us in touch. He's putting together a library of them—a big book of my secret recipes," Michael says.

Michael's son, Matthew, joined the army as a cook and was involved in the 1st Airborne in Iraq. Since Matthew has kept up the cooking tradition, Michael tries to send unusual recipes. One month he may send a recipe for Oyster Rockefeller soup, acquired under the tutelage of a famous Cajun chef and the next an upscale recipe for Veil Oscar. "As a chef, you put things together that people aren't expecting to surprise them," Michael explains.

### Portabella Napoleon

Serve this stylish stack of veggies hot or cold.

#### Ingredients

8 large portabella mushroom caps	large red, green and yellow Holland peppers (one of each)
1 long, wide zucchini	1 large sweet Vidalia onion
1 summer squash	1 c low fat Italian dressing
1 eggplant	

1. Remove the fins from mushroom caps with a teaspoon. Brush off caps, but don't get them wet. Peel the onion and cut round slices 3/4 in. thick. Cut each pepper into fourths. Cut the ends off the squash and slice the long way about 3/4 in. thick. Slice the eggplant and zucchini 1/2 in. thick.
2. Marinate all the veggies in lite or low fat Italian dressing for at least 2 hours.
3. Remove from marinade and place directly on a preheated grill for 2-3 minutes on each side. Be careful not to over cook. Vegetables should be a little firm.
4. Remove from grill and stack in the center of a plate. Use the squash as a base, followed by onion, zucchini, eggplant and peppers. Top off with a cooked mushroom cap. Serve hot or cold. Makes 8 servings.

*Creative cooking isn't just for the experts. Here are a few cooking tricks and tips for food savvy Alphas on a health kick!*

### Hearty Hamburger Soup

An easy-to-prepare fall favorite

#### Ingredients

2 16 oz cans low sodium beef broth	12 oz baby peas
1 large onion chopped	2 12 oz cans stewed tomatoes
1 c carrots chopped	1.5 tsp basil
1 c celery chopped	1.5 tsp oregano
½ lb ground turkey	1 tsp minced garlic
½ lb elbow macaroni cooked	1 tsp tarragon

1. Pour beef broth into a stock pot and bring to a boil. Add chopped onions, carrots, and celery and continue boiling until softened. Add stewed tomatoes with liquid and simmer.
2. Sauté ground turkey in a separate pan and drain fat.
3. Add ground turkey, elbow macaroni and baby peas to stockpot. Season with garlic, oregano, basil and tarragon to taste. Ladle into bowls and serve with crusty bread. Makes 8-10 servings

### Tips from the Kitchen

- Start with an entrée like fish or chicken.
- Use non-stick cooking spray and grill or bake instead of frying.
- Experiment with herbs and spices to enhance flavor rather than add fat and calories with butter, creamy sauces and cheese.
- On occasion, let your veggies take center plate with meatless entrees and protein-rich sides (think beans, hummus and even tofu).
- Don't be afraid to modify recipes. Many baking recipes taste just as good with a few healthy substitutes including applesauce or yogurt for oil, butter or sour cream.

*Surprise everyone at your dinner table with these Alpha-friendly dishes from Michael's recipe vault!*

## Art and Rehabilitation

The Queeny Tower lobby of Barnes-Jewish Hospital is an unlikely location for weekly art classes, but for the patients, caregivers and hospital staff in the Pulmonary Rehab Department, these classes are a source of relaxation and release.

Yvonne Sledge, CRT, a respiratory therapist in pulmonary rehabilitation and current coordinator of the “Lung Transplant Art Program”, explains, “Many of our patients encounter feelings of anxiety,

frustration, boredom and impatience that may come from unfamiliar surroundings, the waiting process and separation from family. These art classes allow patients to engage, create and channel their energy. They also serve as a social outlet.”



The art program began in 1997 when Mickey Stoker, a high school art teacher, decided to pass the time by drawing

portraits during her husband’s daily exercises in pulmonary rehabilitation. Mickey soon began instructing admiring patients and hospital staff, including Yvonne Sledge, who continued the program after the Stokers returned home. Under Yvonne’s supervision, the program has evolved from an ad hoc art class to produce exhibits that have garnered local and regional media attention. Art pieces from patients and staff have been collected and published in a “Transplant Teddies” book. An art quilt for the Respiratory Care Department is on display in the front office and staff members have created a scrapbook to showcase creativity. Freelance drawings, painted birdhouses, spoons and pots have also been displayed.



*Yvonne Sledge alongside a display of patient art.*

Sanskrit for “circle” or “sacred circle”, can be found in many cultures and is used for relaxation, meditation and holistic healing. “Relaxation is for everyone” states Yvonne, “We’re excited to see what the patients and their caregivers will produce.”

Yvonne’s latest project teams up with “Arts In Healthcare” to exhibit works by Cystic Fibrosis and Lung Transplant patients. “Mandalas on Canvas” will showcase collages of mandalas selected and colored by patients. A mandala,

## Transplant Recipients and Donor Families Take on Donor Dash



*John with wife, Kathy, and donor’s mom, Robin, at the Dash.*

John Taylor, a double lung transplant recipient from Phoenix, Arizona, laced up his tennis shoes last July to participate in the annual Donor Dash hosted by the Donor Alliance. John walked the 5K with his donor’s family and the heart recipient from the same donor. “It was an emotional moment,” John says about meeting the heart recipient. “I was prepared to be emotional when I met the family. It never occurred to me that I would be so overwhelmed meeting this fellow.” John received his transplant in January 2008 and both he and the heart recipient have seen exceptional improvement.

“Because of the transplant,” John says, “I went from needing 3+ liters of oxygen at rest to working out 5 days a week. I recently climbed from 11,000 ft to 12,000 ft above sea level at Estes Park, Colorado. It’s amazing what a healthy set of lungs can do and there isn’t a day that goes by that I don’t think about this young man who gave me life. He and his family have given me a tremendous gift.”



*A record-breaking 3,000 participants prepare to show their support in the 10th annual Donor Dash.*



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

## UPDATE ON H1N1 (SWINE) FLU

### INTRODUCTION

The H1N1 influenza virus, also known as Swine Flu, has now been in the US for many months. Since the release of approved vaccines (flu shots) is imminent, an update on the current status of H1N1 flu is appropriate. The article entitled "Swine Flu and the Alpha-1 Community," written by the AlphaNet medical team in April 2009, remains accurate and can be accessed from the AlphaNet homepage ([www.alphanet.org](http://www.alphanet.org)). One of the very best sources of up-to-date information can be found on the U.S. Centers for Disease Control (CDC) website [www.cdc.gov/swineflu](http://www.cdc.gov/swineflu).

People who have Alpha-1 and their caregivers should stay informed about the presence of H1N1 in their communities. Flu is primarily a respiratory infection and respiratory infections can be more severe in people who have the types of medical conditions such as those with Alpha-1.

The regular seasonal flu vaccine is already available and is recommended for most individuals with Alpha-1. As of this writing (late-September 2009), the H1N1 flu vaccine is still under evaluation by the FDA, but recent data suggest that it may be possible to achieve immunity with a single injection, rather than the two injections initially thought to be needed. The H1N1 flu vaccine is still

on-track to be released during the second half of October. It is likely that a nasally delivered vaccine will be available prior to the injectable vaccine. Patients with lung disease due to Alpha-1 and their family members should not use the nasal vaccine. The nasal H1N1 flu vaccine is made from live virus that has been partially inactivated and can cause serious infections in individuals who have a compromised immune system, including people with lung disease. Family members who receive this live virus vaccine can pass the virus to other family members.

The CDC identified five groups that should receive the H1N1 vaccine as soon as it is available:

- Pregnant women
- Healthcare providers
- People between 6 months and 24 years old
- People who live with or care for babies younger than 6 months of age
- People from 25 through 64 years old who have health conditions associated with higher risk of medical complications from influenza (this last category includes many Alpha-1 patients followed by AlphaNet).

You might wonder why individuals greater than 64 years old are not included in these groups. The primary reason is that older individuals appear to have complete or partial immunity already, presumably because they were exposed to a similar flu that struck when they were much younger.

## What are the symptoms of H1N1 (swine flu)?

The most common symptoms include fever, dizziness, cough, runny nose, sore throat and muscle aches. Nausea, vomiting and diarrhea also can occur. The infection may last 10 days.

## How does this flu spread?

Like other types of flu, H1N1 is spread mainly by person-to-person contact. The virus moves from one person to another through the spray when someone coughs or sneezes. People may become infected by touching something with flu viruses on it and then touching their mouth, nose or eyes.

## How is H1N1 (swine flu) diagnosed?

The only way to definitively diagnose this flu is by having your doctor take a respiratory sample (swabbing your nose) and sending this to the CDC lab for analysis. This is not routinely done anymore. Usually, the physician will rely on symptoms, exposure history, and an in-office influenza A test (most commonly from a nasal swab). H1N1 belongs to a class of influenza virus called influenza A.

## What medications are available?

At this time, the CDC recommends use of the antiviral drugs Tamiflu (oseltamivir) and Relenza (zanamivir) to treat infection with the H1N1 virus or to prevent infection if you are exposed to someone with the flu. Antiviral drugs differ in terms of who can take them, and how they are given. For instance, it is recommended that individuals with respiratory problems avoid using Relenza. The CDC has issued

interim guidelines for the use of these drugs and may update these guidelines as the number of infected people changes.

## Suggestions for people with Alpha-1

- See your doctor as soon as you feel ill, especially if you get a sudden high fever, or if someone in your family or work place has flu symptoms. The flu shot you received about a year ago does not protect you from this virus.
- Promptly seek medical attention if you have breathing difficulties.
- Talk to your doctor to determine if you should take an antiviral drug to prevent or treat infection. Remember, antiviral medications only work if taken within 48 hours of the start of symptoms or exposure to someone with the flu.

## Suggestions for staying healthy

- Wash your hands often with soap and water, especially after you cough or sneeze. Use an alcohol-based hand cleaner when soap and water are not available.
- Cover your nose and mouth with a tissue when you cough or sneeze; then throw away the tissue.
- Do not touch your eyes, nose or mouth.
- Keep yourself and your children away from sick people.
- If you or your child become sick stay home from work or school.
- Stay well hydrated. Becoming dehydrated is a common and potentially serious complication of all types of flu.

# CLINICAL COLUMN

## Portable Oxygen Concentrator Updates for Airline Travel

By Teresa Kitchen, BSN, RN, AlphaNet Clinical Nurse Manager  
Great news for Alphas who need to travel by airplane with oxygen!

The rules for airline oxygen travel changed as of May 13, 2009. All airlines which land or take off in the US will now be required to allow approved, individually-owned Portable Oxygen Concentrators (POCs) to be carried on and used aboard the plane. You can get information on the new airline oxygen rules from the Airline Oxygen Council of America (AOCA) at [www.airlineoxygenCouncil.org](http://www.airlineoxygenCouncil.org). The AOCA website provides the names of approved concentrators, rules, travel tips and, most importantly, tells Alphas how to report a problem with an airline concerning your oxygen needs. A link for the AOCA can be found on the Alpha-1 Foundation website at [www.alphaone.org](http://www.alphaone.org).

As always, if you have any questions about Alpha-1, please don't hesitate to contact your AlphaNet Coordinator.

## 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](mailto:humanresources@alphanet.org)

## Upcoming Community Events

November 8

Alpha Walk and Run  
Miami, Florida

November 14

Alpha-1 Education Day  
Ann Arbor, Michigan

November 14

Swirl for Alpha-1  
Newbury Park, California

November 14

Vicki Joseph Celebration of Life  
Springfield, Massachusetts

The Alpha-1 Education Days are co-sponsored by the Alpha-1 Foundation and the Alpha-1 Association.

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

The Alpha-1 Association is dedicated to improving the quality of life for Alphas through programs and services, including a support group network, community outreach, a genetic counseling center, an education day series, a national education conference and a grass roots advocacy network. For more information, or to become a member of the Association, please visit [www.alpha1.org](http://www.alpha1.org) or call 800-521-3025 ext. 16.



2937 SW 27th Ave, Suite 305  
Coconut Grove, Florida 33133  
800-577-2638 • [www.alphanet.org](http://www.alphanet.org)  
**Return Service Requested**

