

# WELCOME TO ALPHAVILLE

*Skinny Little Reference Guide™* Series

NOW AVAILABLE IN SIX LANGUAGES

## ESPAÑOL

¿Qué son las exacerbaciones pulmonares?



## PORTUGUÊS

Comprender as Exacerbações Pulmonares



Alphas Serving Alphas

## FRANÇAIS

Comprendre l'Exacerbation Pulmonaire



## DEUTSCH

Was sind Verschlimmerungsschübe bei Lungenkrankheiten?



www.AlphaNet.org

## ITALIANO

Comprendere le esacerbazioni polmonari



## ENGLISH

Understanding Pulmonary Exacerbations



AlphaNet

# Community Calendars

## Alpha-1 Association Education Day

co-sponsored by the Alpha-1 Foundation

November 16  
Anaheim, CA

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: (800) 521-3025.

## Alpha-1 Foundation Event Calendar

Nov. 9 – Step Forward for Alpha-1 Walk  
West Palm Beach, FL

Nov. 9 – Team Alpha-1 Rock & Roll  
Marathon  
Savannah, GA

Nov. 9 – Team Alpha-1 California  
Los Angeles, CA

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

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

## CONGRATULATIONS!

AlphaNet would like to acknowledge the following SFS Monthly Sweepstakes Drawing Winners:

**March 2013:**  
Doug Miller  
Devils Lake, ND

**April 2013:**  
Peter Cook  
Jamestown, RI

**May 2013:**  
David Davis  
Avon Lake, OH

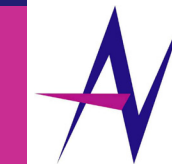
**Grand Prize Winner (Year 2):**  
William Chapman  
Gettysburg, PA

## Story Ideas?

Do you have an interesting story that you think would make a great article for an upcoming issue of *The AlphaNetter*?

If so, please submit any ideas, comments and/or suggestions to Christine Lanser at [clanser@alphanet.org](mailto:clanser@alphanet.org).

AlphaNet, AlphaNetter, Big Fat Reference Guide and Alphas Serving Alphas are registered trademarks of AlphaNet, Inc. ©2013



Fall 2013

The AlphaNetter is a publication of AlphaNet, Inc.

Toll free: 800-577-2638  
Fax: 305-442-1803  
[www.alphanet.org](http://www.alphanet.org)

**COORDINATORS:**  
Mike Benn 877-466-0848  
mbenn@alphanet.org (KY, WV)  
Kathleen Brown 877-339-2685  
kbrown@alphanet.org (AT-Large)  
Patti A. Brown 877-264-7470  
pbrown@alphanet.org (TX)  
Cathy J. Button 877-339-2681  
cbutton@alphanet.org (AT-Large)  
Linda L. Cay 877-710-0915  
lcaly@alphanet.org (MN, WI)  
Victoria (Vicki) S. Cameron 888-526-0351  
vcameron@alphanet.org (ANCs)  
Susan Clarke 855-742-5240  
sclarke@alphanet.org (AT-Large)  
Elizabeth A. Eich 877-339-2681  
eich@alphanet.org (AT-Large)  
Doreen Flock 877-860-8694  
dflock@alphanet.org (MI)  
Peggy Iverson 855-628-4145  
piverson@alphanet.org (Zemaira, Central USA)  
Lisa Kosak 855-814-3914  
lkosak@alphanet.org (Zemaira Southeast)  
Junior (JR) Lawler 877-901-5751  
jlawler@alphanet.org (IA, KS, OK)  
Patricia (Pat) E. MacInnes 877-277-7931  
pmacinnes@alphanet.org (NY)  
Jean M. McCathern 888-526-9077  
jmccathern@alphanet.org (PA)  
Celeste B. Morris 877-330-4506  
cmorris@alphanet.org (IL)  
Darrell Nail 800-837-4244  
dnail@alphanet.org (AT-Large)  
Miguelina Ortiz 855-230-4241  
morte@alphanet.org (Bilingual, At-Large)  
Diana J. Patterson 888-399-0443  
dpatterson@alphanet.org (South FL, PR, USVI)  
Barbara J. Pussey 800-745-3004  
bpussey@alphanet.org (Zemaira, Western USA)  
Sandy L. Singleton 877-898-8630  
ssingleton@alphanet.org (CA, HI, AK)  
Kathleen (Kathie) D. Sivesind 866-244-1026  
ksivesind@alphanet.org (NW, WA, OR)  
Jesse Strickland 866-224-6637  
jstrickland@alphanet.org (IN)  
Sue K. Smith 888-883-2991  
ssmith@alphanet.org (OH)  
Kay Swift 877-742-9078  
kswift@alphanet.org (NE, ND, SD, CO)  
Patricia (Patty) Tew 877-271-3001  
ptew@alphanet.org (GA, North FL)  
Gayle Tipper 877-982-5742  
gallison@alphanet.org (NC, SC)  
Jane Totten 866-477-1552  
jtotten@alphanet.org (VA, MD, DE, DC)  
Angela Town 855-898-1898  
atown@alphanet.org (ME, NH, VT, CT, NJ)  
Lisa Trepper 855-230-4242  
ltrepper@alphanet.org (Zemaira Northeast)  
Douglas (Doug) K. Turley 877-943-9828  
dkturley@alphanet.org (TN, MO)  
Marilyn Wagner 866-556-6622  
mwagner@alphanet.org (AL, AR, LA, MS)  
Fred C. Walsh 800-791-3194  
fcwalsh@alphanet.org (MA, RI)  
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 rsandhaus@alphanet.org  
Terry L. Young, Management Advisor  
800-278-1804 tyoung@alphanet.org  
Jim A. Quill, General Manager  
888-795-6393 jqull@alphanet.org  
Bonnie S. Boyd, BS, RN, Director of Disease Management & Clinical Research  
877-913-8141 bboyd@alphanet.org  
Jana S. 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  
Monica M. Wahler, Human Resources Director  
800-577-2638 ext. 247 mwahler@alphanet.org  
Edward J. Parker, IT Manager  
800-577-2638 ext. 257 eparker@alphanet.org  
Veronika V. Dossava, Accountant  
800-577-2638 ext. 209 vdossava@alphanet.org  
Patrick M. Lunn, Controller  
800-577-2638 ext. 249 pmlunn@alphanet.org  
Elena J. Tenzel, Executive Assistant  
800-577-2638 ext. 271 etenzel@alphanet.org  
Ashley L. Chase, Communications Specialist  
800-577-2638 ext. 243 achase@alphanet.org  
Christine A. Lanser, Communications Specialist, Editor

# The AlphaNetter

## Alpha's Therapy Dog Brings Joy to Young and Old

For Alpha Karen Williams of Muskegon, Michigan, helping others in her local community has gone to the dogs! Karen's beloved 3 and half year old American Pit Bull Terrier, Hoss, is making a difference by bringing smiles to everyone from young burn victims to nursing home residents in his role as a registered therapy dog.

After working for thirty years with individuals with disabilities, Karen, who lives with her husband Ralph, sought out a way to continue helping her community in any capacity possible. For Karen, her motivation to serve comes from a higher power, "I do this all with God's will." In order to fulfill this desire, Karen decided to involve her dog Hoss by registering him as a therapy dog. "I knew Hoss would be great as a therapy dog and he would be a benefit to people. More than that, though, he would motivate me to get out of the house if I knew we were going to be providing a service by visiting the nursing home or helping out children in need," Karen noted.

With that in mind, Hoss underwent a series of screenings to determine his eligibility as a therapy dog. As part of the training, Hoss performed a screening exercise where he had to walk beside a wheelchair and a walker. He was also given certain scents to smell, which included alcohol and baby powder, to determine if he could tolerate them without reacting too much, as these smells were typical of a nursing home environment. Furthermore, Hoss had to crawl to the top of a bed without pulling or unplugging any tubing and catheters lines, which are, in many cases, attached to nursing home residents. He also had to be able to get along with other animals such as birds and cats and even fellow dogs. Hoss successfully completed his training and was

certified as a registered therapy dog.

From that point on, Karen was able to take Hoss to community outreach events around town. Karen and Hoss make a weekly visit to the nursing home as part of a program known as "Memory Matters". Hoss is the resident superstar and everyone at the nursing home, including the



Karen Williams with her dog Hoss

patients, employees and even the director, look forward to Hoss' regular visits. "Everyone loves Hoss and they are more likely to remember his name before they remember mine!" Karen said.

Clearly, Hoss has made a favorable and lasting impression on the nursing home residents that he visits. More than just serving these individuals, Karen and Hoss make special visits to a camp for children who have suffered from severe burns.

Moreover, Karen and Hoss participate in a local library program known as "Ruff Readers," where Hoss looks on intently as children read a variety of library books.

Through the many programs they participate in, it seems evident that Karen and Hoss have certainly made a wonderful impression on their local community and are living up to Karen's goal of serving the greater community. Ultimately, Karen, who has an FEV1 of 25%, is not allowing her Alpha-1 deter her from performing good works, and having Hoss by her side certainly makes it all the more worthwhile for her.

"Hoss brings a smile to peoples' faces and often when I'm chatting with someone, another person off to the side will inch closer to Hoss to pet him and the second he sees this person coming toward him, his tail starts wagging faster and faster! Everyone just loves Hoss!"

## ~ Rocking Through Rehab ~



### One woman's journey through pulmonary rehab, the fitness gym and real life

By: Cheryl Ann Ewing

Exercise and I have not been life-long friends. I attended school before Title IX, so I avoided a lot of PE classes because there were no facilities for girls. That was fine with me; I enjoyed the library more. I never learned to ride a bike, never played tennis. I did some sport walking, but that was always worked in around the office, care and feeding of two children, and, in later years, teaching five different classes each day.

My Alpha-1 Antitrypsin Deficiency diagnosis 13 years ago certainly explained to me why walking, climbing stairs and most everything else were becoming harder for me. My exercising was limited to walking (weather permitting) and some Pilates mat work. Exacerbations would halt my exercising, and, when I was better, I would have to build stamina all over again.

After retirement and a complicated long-distance move, I found myself catching up on all the books I hadn't read during my work years and all the foreign films I hadn't seen. Additionally, I volunteered for a library research job cataloging some rare books. If you think about all of those activities, you'll find one common denominator: I was sitting a lot.

A long-lasting exacerbation of bronchiectasis last winter hit me hard. I was in the most weakened state of my adult life. The condition eventually abated, but I found myself with very little energy or stamina. I had become progressively deconditioned, and I saw this clearly in the dismal results I received on a pulmonary function test taken during that time. I asked for a referral to pulmonary rehab.

Pulmonary rehab is an equal-opportunity experience. Everyone gets to play; no one sits it out. After a thorough assessment with a nurse, the nurses and therapists introduced me to a recumbent bike, a cross trainer and an arm ergometer. As it happens, all three of those machines do, in fact, start in a seated position, but large muscle groups move constantly and against progressively higher resistance.

One of the best things about the formal rehab setting is the regular monitoring by health

professionals. Patients have their vital signs and oxygen level checked upon arrival and before departure. Moreover, heart rate, blood pressure and oxygen levels are checked as patients use each of the machines, do walking and perform exercises. If there are any problems with these readings, patients stop, sit and regulate their breathing until all is well. Thus, patients do not hurt themselves by doing too much too soon. Additionally, patients come to recognize when their heart and oxygen rates indicate dangerous levels and when readings indicate the normal results of exercise. This insight encourages people to keep exercising with confidence.

Pulmonary rehab works on the principle of slow progress. Each session begins with a chart review detailing machine usage, duration of work and resistance levels. Lengths of exercise and/or intensity levels go up slowly each session. For example, I began using the cross-trainer for six minutes at resistance level two. After my ten weeks, I was setting the machine at level four and exercising for 20 minutes. This slow progress allows each patient to improve strength and endurance and to change what is possible for herself/himself.

My first rehab session was about 30 minutes long. After ten weeks, I was exercising for about an hour and a quarter. I was using each machine longer and with greater resistance levels. In week three, I began walking the length of the clinic and back again. I started with three round trips (about 1500 feet) and ended up walking ten round trips (just about a mile). I could not believe the work I was doing and how good I felt about it.

We tend to avoid exercising because the sensation of shortness of breath is uncomfortable. Yet, we all have been told that exercise improves the heart's ability to both pump blood and to circulate that blood throughout our body. It increases energy levels and muscle strength. And, it improves shortness of breath, which is often what keeps us from exercise and from daily activities.

Within a few weeks, I began to notice some nice changes:

- I no longer pant when I climb the stairs (16

steps) in our home.

- For the first time I have some definition to my biceps.
- I am sleeping better and more soundly.
- I can carry all but the heaviest bags of groceries into the kitchen from the car.
- I no longer have bat-wing upper arms (good riddance).
- I can lift and carry larger potted plants.
- I have more strength and stamina.

But, rehab ran its course after ten weeks, and I wanted to maintain the program as best I could. I visited the gym in our neighborhood and made notes on all of the machines available to me. Working with that list, my rehab therapist designed a program for me that included both cardiovascular exercise (continuing my rehab work), as well as weight training exercises (new for me) for bone strength. She set starting points for the number of repetitions as well as some goals in resistance levels and weight amounts towards which I would work.

If you've not been a gym regular, all of the weight equipment can be daunting at first. It is most helpful to have a trainer or a friend who is familiar with the equipment and who can help you to adjust the seats and the various arm and leg pads, as well as resistance levels and weight amounts. Having someone with you also allows for a check of both posture and breathing. It is easy to make mistakes with these machines; for instance, I found myself raising the base of my spine while doing leg lifts. My friend spotted this, and we adjusted the seat so that I was able to do the lifting correctly without reducing the weight.

On my three gym days, my cardiovascular exercise is the recumbent bike. I also do the weight training on those days and then rest those muscles the next day. So, on my non-gym days, my cardio exercise is a 30 minute walk in my neighborhood. That's it—not really complicated, but it changed my life and how I do my daily work.

The media use the word "transformational" in many different contexts. But the root noun of that word, *forma*, has many meanings. It can simply refer to change in a person's body. It may also signify a quality or condition of a life. And, finally, this word can denote a pattern or a model. My participation in pulmonary rehab did, in fact, transform my body and my stamina. It also transformed the quality of my life. And, finally, it transformed the pattern of my life. I put exercise first in my day now, and I find myself looking forward to it.

One evening at dinner, I was trying to explain to my husband how much stronger I felt and how, subtly, I felt better able to cope with what life handed me. I wasn't explaining it well. He reminded me of the book, *The Little Engine That Could* and remarked that, previously, I had often met situations with an attitude of, "I can't; that is too much a pull for me," as quoted from the book. He observed that, since rehab, however, I had begun to face life with the attitude, "I think I can."

None of us knows what life holds in the future. But, I know that the "new normal" for me is a fit and an active woman who exercises regularly and who is more likely, when challenged, to be able to respond, "I think I can."

Do you have questions regarding the Affordable Care Act? If so, please contact AlphaNet Coordinator Diana Patterson at 888-399-0443.

We need your VOTE!  
Alpha Richard Johnson is a finalist for the NASCAR Foundation's 2013 Betty Jane France Humanitarian Award. Richard needs your vote to win \$100,000 to the charity of his choice, The Alpha-1 Foundation!  
Log-on to <http://www.nascar.com/award> to cast your vote for Richard Johnson.  
Voting begins on October 1, 2013 and ends on December 4, 2013 at midnight.

## Clinical Corner

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

### Medicare Reminders

It's Medicare Part D time of year again! Medicare Part D is the Medicare program that covers prescription drugs and the options can be confusing to many of us. Remember, you have just one time each year to make changes. You'll want to evaluate your current plan against any changes in your medications to be sure that your current plan will continue to cover the medications you need at a price that works for you. Many plans change their coverage and pricing from year to year. Here are a few things to know:

**\*Open Enrollment for 2014 is from October 15th - December 7th.**

\*View the Medicare website at [www.medicare.gov](http://www.medicare.gov). It has great information to help with evaluating and choosing a plan or you can call 1-800-MEDICARE (1- 800-333-4114).

\*Communicate with your infusion providers, so that they can verify that you have coverage and can assist you with choosing the best plan for you.

\*Gather your medications or compile a list of all medicines that you are taking so that you can determine which Medicare plan will meet your needs for all the types of medications you need; pills, inhalers and augmentation therapy.

\*Communicate early with your pharmacy, physician and augmentation therapy provider if you are nearing Medicare age or if you have any type of insurance change. This will help minimize any interruption in your infusion.

If you have further questions, please don't hesitate to call your AlphaNet Coordinator for assistance.

## Start of Flu Season Means Flu Shot Time

Flu season is, once again, upon us and now is the time for you to protect yourself from this illness. The single best way to prevent the flu is to get vaccinated each year. The Center for Disease Control (CDC) recommends that everyone who is at least 6 months of age get a flu vaccine, and it is especially important for Alphas to get vaccinated.

The CDC notes that there are 3 different flu shots available. In addition to the regular flu shot, there are other flu shots given with a needle, including a high-dose flu shot for people 65 and older and an intradermal flu shot for people 18 to 64 years of age.

- The regular seasonal flu shot is "intramuscular" which means it is injected into muscle (usually in the upper arm). It has been used for decades and is approved for use in people 6 months of age and older, including healthy people, people with chronic medical conditions and pregnant women. Regular flu shots make up the bulk of the vaccine supply produced for the United States.
- The high-dose vaccine is for people 65 and older which also is intramuscular.
- The intradermal vaccine is for people 18 to 64 years of age, which is injected with a needle into the "dermis" or skin.

Ultimately, the type of flu shot that your local pharmacy or your general physician will carry may differ from location to location, but it is important to note that all are equally safe and effective at preventing the flu. Please consult your doctor or pharmacist for the best option for you.