



WINTER
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The AlphaNetter

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INHALERS

TRANSITION TO NEW DELIVERY SYSTEM

For more than 50 years, metered dose inhalers, such as albuterol, have used CFC (chlorofluorocarbons) as a propellant to deliver these vital spray medications. CFCs are known to help deplete the ozone in our atmosphere and have been banned since 1987. Medical inhalers were exempt from this ban until manufacturers could develop, test, produce and distribute an effective alternative.

The time has come and the new propellant is known as HFA (hydrofluoroalkane). The new inhalers will still look the same, but will be very different on the inside.

The speed in which the medication leaves the canister is slower and some have reported feeling it is "not strong enough to push open their airways." It is important to keep in mind that the force of the spray is not what causes airways to open, it is the medication that is delivered. This new system delivers essentially the same dose of the same medication.

The new HFA inhalers also need to be cleaned more frequently than their predecessors, since the medication tends to clog the exit port of the applicator. Priming requirements have also changed and vary by product, so reading the instructions and discussing it with your pharmacist, nurse and/or physician is important.

The good news is that the new inhalers offer benefits beyond being better for the ozone. They deliver the medication dose more correctly and allow for more variety of treatment options.

Unfortunately, the cost is higher, due to the development of the new system, and generics are not yet available. Check with your Coordinator if you need financial assistance.

"I urge every Alpha to be aware of this change and be prepared before they have any problems," said Dr. Robert A. "Sandy" Sandhaus, Medical Director of AlphaNet.

ILLINOIS ALPHA HAS A PARTY-LINE

Chicago-area Alpha Ken Thime knows how to keep in touch. Ken keeps in contact with members of his church by making special calls on their birthdays; and he makes those calls from all around the country. A retired carpenter, he travels frequently (and was off to Mexico when we spoke to him) and spends several months a year in the warmer climate of Arizona. His fellow parishioners are important to him, and he has organized his list by month and age to facilitate the calls he makes on behalf of the 200-plus congregation. The most unusual location from which Ken placed a call was while cruising Alaska's Inside Passage.

Church and a strong faith in God are important to Ken and his wife Pat. Pat shared an interesting story about when Ken was first diagnosed, "we had never heard of Alpha-1 or infusions, and

Alpha Ken Thime during his recent trip to Mexico.



didn't know where to begin for help."

That same week she attended a church deacon's meeting and at the conclusion of business, when the participants share joys and concerns, Pat shared her concerns about Ken's diagnosis. The deacon sitting across the table said she was a home care nurse and her company gave Prolastin infusions and that she would help.

Pat said, "How's that for Asking and Receiving?"

Ken knows how to enjoy life while sharing his joy and faith with others.

A POET AMONG US

Diann Blakely has been a poet ever since first grade. Defining her vocation as "something that chose me, rather than one I chose," Diann is an award-winning author with three published books of poetry.

Following her life's journey through her native South to New York City, Boston, and her diagnosis with Alpha-1 eight years ago, Diann has returned to her Southern roots. She and her husband, the writer Stanley Booth, now live in Brunswick, Georgia, in a Low Country cottage open to the views and breezes of the river.

Although she says her "life changed overnight" with her first hospitalization and subsequent diagnosis, Diann reports that even though she is oxygen-dependent, her quality of life is excellent. She defines herself as a "homebody" who is "deliriously happy to stay in pajamas and read and write all day."

Through the years, Diann has also been interested in visual arts, taking a B.A. in art history from Sewanee (University of the South) in Tennessee. After receiving a master's degree in

Successful poet, Diann Blakely now resides in the Low Country near Savannah.



literature from Vanderbilt, during her mid-eighties years in Boston, she audited classes with two Nobel laureates. Diann was also fortunate to have other wonderful teachers and mentors at Vermont College, where she earned a Master of Fine Arts in 1990. Poets never make a living writing, as she'll tell you, thus until her initial bout of serious, disabling illness in 1997, she worked in a variety of academic settings, including administrative posts and teaching creative writing at the high school and college levels. As her health permits, she continues to write, working on a fourth book, and also as a freelance reviewer.

"Being a poet has helped me cope with Alpha-1," said Diann. She describes poetry as "the expression of the human heart, one soul whispering to another."

To find Diann's current books of poetry check on Amazon.com and enter her name in the search field.

ENTREPRENEUR CRAFTS NEW CAREER

Randy Lawson loves kids. With a family member in the business of making table legs for daycare centers, Randy hatched a plan to sell the toddler tables on-line for the manufacturer. His research led him to the conclusion there was very little information easily available for daycare providers. In a move Randy calls "a matter of necessity being the mother of invention," he set out to fill the niche in 2001.

After teaching himself the unique HTML code you need to communicate through the Internet, Randy began collecting a broad range of information relevant to providers of daycare. The colorful site is jam-packed with information on topics and issues such as product recalls, governmental guidelines, funding sources, resources and newlinks. He also began to attract other companies, and is now representing up to eight manufacturers of factory-direct daycare products.

The site www.daycareuniverse.com has grown steadily about

Entrepreneur Randy Lawson logs in productive time on his computer.



20% per year and in the past two years has doubled in sales. It takes Randy about 15-20 hours a week to keep the site updated.

"It's the perfect job for a low activity person using O₂" said Randy. "What better way to get up off the couch is there than to talk to people all over the country and, at the same time, help keep our children safe and happy."

Randy's latest venture is dedicated to selling board games and video games through Amazon via www.thegamesource.com. Randy says his new site is still a work-in-progress since the gaming market is very competitive. He plans to donate 25 percent of his profits from the gaming site to the Alpha-1 Foundation in support of research. Any Amazon purchase linked through his site will be included in his total calculation.

A SINGLE CIGARETTE DESTROYS ALL THE ALPHA-1 ANTITRYPSIN IN THE LUNGS.



Cigarette smokers inhale over 400 toxins and 43 known carcinogens every time they puff. As smoke enters the respiratory tree and lungs, it causes irritation and triggers inflammation. This inflammation causes the body's defenses to send white blood cells to the area. While performing their normal function, the white blood cells release a powerful enzyme, known as neutrophil elastase. Neutrophil elastase is destructive to unprotected lung tissue. You probably know, alpha-1 antitrypsin (AAT) is the protein in our bodies that provides protection to the lungs by neutralizing this powerful enzyme.

We know the chemicals created from burning tobacco destroy alpha-1 antitrypsin. In fact, a single cigarette destroys all the alpha-1 antitrypsin in the lungs. For Alphas, the exposure to cigarette smoke accelerates damage to the lungs, and symptoms may develop 30 years ahead of someone with "normal" lungs.

-adapted from *The Big Fat Reference Guide*

NEW PATIENT SERVICES COORDINATORS JOIN ALPHANET

AlphaNet is pleased to welcome five new Coordinators. Dan Clark will cover Michigan; Sue Smith will assist Ohio and West Virginia Alphas; Jenny Faull works with Barb Pusey to assist the growing number of Zemaira users; and Jim Rapp and Marianne Mullen are newly assigned Coordinators At Large assisting Alphas when their regular Coordinators are unavailable.

DAN, who lives in West Bloomfield, Michigan, NW of Detroit is a veteran with a background in law enforcement, having worked for the City of Troy Police Department and the Oakland County Sheriff's Office.

A double-lung transplant recipient, **SUE** retired from teaching after 19 years of working with fourth grade and special education students. She lives near Lake Erie in Painesville, Ohio. Sue just successfully competed in her first transplant games.

JENNY (who was featured preparing for a marathon in the Winter 2007 AlphaNetter), is a former accountant, business executive and mother of four from Grove City, Pennsylvania. As previously reported, Jenny often says, "It's a good day for a walk."

A past president of the North Texas (Dallas-area) Alphas support group, **JIM** has also been a very active volunteer with pre and post transplant patients. A seven-year, double transplant veteran himself, Jim brings AlphaNet experience in marketing and customer service from a career in management with the electronics industry.

A "retired" registered nurse, **MARIANNE** brings her Alphas more than 25 years of clinical nursing skill, almost a decade of case management/utilization review experience, and many years as a volunteer Alpha-1 support group leader. She lives in Tucson, Arizona.

"These new Coordinators are an impressive group and we welcome them to our already fabulous, dedicated team of Alphas serving Alphas,"

said Terry Young, AlphaNet General Manager.

To find their contact information, check the list on the front page.



ANTIBIOTICS AND TENDON PROBLEMS – FDA ISSUES NEW WARNINGS

by Robert A. “Sandy” Sandhaus, MD, PhD,
FCCP, Medical Director, AlphaNet

The drugs we take can improve our health, but can also have known, as well as unexpected, risks.

This is certainly true for antibiotics, which may provide life-saving benefits, but may cause life-threatening complications in a small percentage of people who take them. We all know of people who have had severe allergic reactions to antibiotics or other drugs. In addition, antibiotics can change the normal bacteria that live in the intestines in ways that can lead to an overgrowth of more dangerous bacteria leading to severe complications.

In the 1990s it was found that people taking Cipro (ciprofloxacin) had an increased risk of inflammation of the tendons (tendonitis) and, more rarely, tendon rupture. The tendon most commonly affected was the Achilles tendon, the one that connects the back of the heel of the foot to the calf muscle. It was soon recognized that all the antibiotics related to Cipro (the fluoroquinolones) have the potential to cause these same problems. Since 1996, the US Food and Drug Administration (FDA) has required that all makers of these fluoroquinolone antibiotics place a warning in their packages that tendon problems have been reported with this group of antibiotics. It is suggested that these antibiotics be stopped at the first signs of tendon problems and that, if possible, other antibiotics should be considered for a given infection. Of course, physicians and patients have to remember that other antibiotics might have their own, even more common or severe problems.

Recent evidence has suggested that certain risk factors may increase the likelihood that a patient receiving Cipro, or one of the other fluoroquinolone antibiotics (such as Levaquin, Avalox, Factive, Norozin, and Floxin) will have one of these tendon-related problems. These risk factors include being a recipient of lung, heart, or kidney transplants; being older (more than 65 years old); and using corticosteroids on a chronic basis (examples of corticosteroids include prednisone, medrol, Solu-Medrol,

Celestone, and Depo-Medrol). In addition, people with a previous history of tendon problems and people who engage in vigorous physical activity are also at some increased risk when taking these drugs. It is not known if the use of inhaled steroids increases this risk of tendon problems, but this seems unlikely except at very high doses of inhaled drug. This new information has led the FDA to rule that the information materials for all fluoroquinolones will have to include a “black box warning” informing physicians and patients of these additional risks for tendon problems.

How frequent are these complications? In the general population not on a fluoroquinolone, these types of tendon problems are seen in about 1 out of every 100,000 individuals. In patients receiving fluoroquinolones this increases to 1 out of every 25,000 to 30,000 individuals. Since many of these fluoroquinolones are now available in generic forms, it is important to know their generic names (the brand names are listed in the previous paragraph): ciprofloxacin, moxifloxacin, gemifloxacin, norfloxacin, and ofloxacin.

This is a new ruling by the FDA and most package information has not yet been changed. Therefore, we do not know the actual wording of the “black box warnings” that will be required to be placed in all information about the fluoroquinolones. Many individuals with Alpha-1 have received these antibiotics during their lives and some have received them on many occasions. Naturally, Alphas will wonder whether they should take these antibiotics in the future. There are many instances in which another type of antibiotic might be as effective as a fluoroquinolone. Whether an alternative non-fluoroquinolone antibiotic is safe for you, or as effective for you, is a decision that you will need to make with your physician or healthcare provider. Given the fact that fluoroquinolones are among the most widely prescribed antibiotics in the world, these will be very frequent discussions indeed.



Being involved in clinical research is one of the most important ways in which Alpha's and their families can help find a cure for Alpha-1. It's easy, get involved!

CSL Behring is currently looking for persons diagnosed with Alpha-1 to participate in a research study. This study is evaluating the long-term (2 year) effectiveness of intravenous augmentation therapy with Zemaira. Subjects who enroll will randomly be assigned to receive either placebo or active drug. The costs related to study procedures, drug, and travel will be paid by the sponsor.

Research sites are located throughout the US. If you or someone in your family meet these criteria, and are willing to consider participating in this study, it's easy to find out more. *Call Bonnie Boyd RN BS, AlphaNet's Director of Disease Management and Clinical Research, toll free at 1-877-913-8141 or email her at bboyd@alphanet.org*

In order to enroll in this study, certain criteria must be met. Although not a complete list, some of these criteria include:

- 1. Age 18 - 65*
- 2. Documented diagnosis of Alpha-1*
- 3. Must have moderate to severe emphysema*
- 4. Can't be a current smoker (no tobacco in past 6 months)*
- 5. Can't have participated in another research study within the past month*
- 6. Can't have had a lung transplant or other lung surgery*

ANDREW STEELE AND GRANT WOOD NAMED TO ALPHANET BOARD

The Board of Directors of AlphaNet, Inc. has elected Andrew “Andy” Steele of Fort Myers Beach, Florida and Grant M. Wood, from Salt Lake City, Utah to multi-year terms on it’s Board of Directors.

Including Steele, more than two-thirds of the AlphaNet Board members are Alphas.

Steele became aware of AlphaNet as a grateful member of the patient service coordinator network.

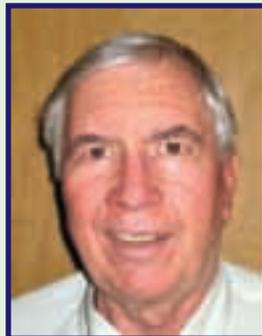
“AlphaNet was very helpful in my own life,” explained Steele. “The organization is an excellent model for anyone with an immune-centered disease. I was really impressed, and that’s what got me interested in becoming involved.”

Originally from Pennsylvania, and an electrical engineer with an MBA, Steele transitioned into a second career as a land developer and entrepreneur. Describing himself as being in an “on the job retirement program”, he currently invests in a number of ventures, including Fleamasters Fleamarket in Fort Myers.

An expert in the information technology field, Grant Wood is Senior IT Strategist with the Intermountain Healthcare Clinical Genetics Institute. Holding a degree in computer engineering from Arizona State University, Wood has become well known in his field, and is a frequent speaker with a number of published articles to his credit.

Wood became aware of AlphaNet while presenting at a Genetic Alliance conference on the topic of family health history and genetic data stored in electronic records. Although he had previously known of Alpha-1, meeting John Walsh at the conference was the first time he had ever met anyone with the disorder.

“The people I’ve met at AlphaNet are so professional and dedicated in serving the Alpha-1 community, that it’s quite an honor to be asked to work with this organization,” said Wood. He hopes to be able to assist in the development of new systems to help Alphas better manage their condition.



Andrew “Andy” Steele



Grant M. Wood

CLINICAL CORNER

Preventing Infection: Techniques for Infusions

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

Preventing infection may be the single most important thing an Alpha can do to maintain their health. For Alphas’ with lung disease receiving augmentation therapy, this means that you and your nurse must be diligent with the procedures used during your infusion to insure that they are clean and germ free.

Most drug preparation and infusion procedures should be completed using “aseptic” or clean technique with one essential goal, to protect you from infection and to prevent the spread of germs. The most common situations that call for aseptic measures during an infusion include: pooling augmentation therapy, inserting a peripheral catheter or removing a port needle.

Here are a few helpful reminders for you and your nurse.

- Identify and clean a designated work area.
- Gather all of the supplies and then thoroughly wash your hands.
- Wear non-sterile*, medical-type gloves when placing a peripheral IV catheter.
- Wear non-sterile*, medical-type gloves to mix and pool your augmentation therapy.
- Use an alcohol wipe for each vial of medication and make sure to vigorously wipe the rubber seal of each vial and allow it to dry.
- Use one alcohol wipe for each vial of medication. (The normal weekly infuser should be using 1 box of alcohol wipes per quarterly order. A box contains 200 wipes.)

**Non-sterile gloves come bundled in multi-packs or boxes.*

If your infusion is given through a central catheter or port, “sterile” technique procedures, which are even more protective than “aseptic” technique, must be used to access your port safely to reduce the risk of infection. “Sterile” technique includes the use of sterile supplies, including sterile gloves, which are usually packaged individually.

If you or your nurse has questions about proper aseptic or sterile technique during infusion with augmentation therapy, please feel free to contact me. I am always willing to assist in teaching patients or to contact your nursing agency for education on infusion technique and supplies or any questions about your augmentation therapy.

If you have any questions or clinical topic you think all Alphas should learn about in the next issue of the AlphaNetter, please contact Teresa Kitchen at TKitchen@alphanet.org or 1-888-553-0093.

Calendar

Alpha-1 Foundation & Team Alpha

MARCH 1-31

USA
Celtic Challenge

MARCH 13

Braintree, MA
Celtic connection: Dinner & Entertainment

MARCH 30

Montclair, NJ
Jeans for Alpha-1 Genes @ School

MAY 9

New York, NY
George Washington Bridge Walk

MAY 15

Denver, CO
Get the Scoop on Alpha-1 Ice Cream Event

JUNE 8

New York City
Liver Walk at Battery Park

JUNE 27

Santa Ines, CA
Lung Association Breathe Easy Ride

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

Alpha-1 Association Programs & Activities

MARCH 21

Alpha-1 Education Day
Los Angeles, CA

APRIL 25

Alpha-1 Education Day
Jacksonville, FL

AUGUST 8

Alpha-1 Education Day
Denver, CO, PA

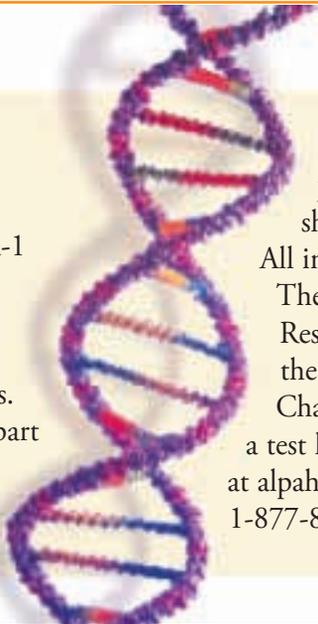
**Save the Date – Alpha-1 Association 2009 National Education Conference
June 5-7 San Francisco, CA**

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

Alpha-1 Coded Testing

Free genetic testing is available through the Alpha-1 Coded Testing (ACT) Trial. The test, to identify individuals with Alpha-1 Antitrypsin Deficiency, is a simple finger-stick and can be completed at home with results returned directly to participants.

Anyone can request to be tested. The test is part of a research study to evaluate perceived risks and benefits of genetic testing. Participants, or the



participant's guardian, must answer a short pre and post-test questionnaire. All information and results are confidential. The study is being conducted by the Research Registry Coordinating Center at the Medical University of South Carolina in Charleston. For more information or a test kit, e-mail the Registry Coordinator at alphone@muscc.edu or call toll free: 1-877-886-2383.



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