

FAA OKs Four More

Portable Oxygen Concentrators

The Federal Aviation Administration (FAA) announced January 8, 2010 that passengers needing medical oxygen now have the option of using four additional portable oxygen concentrators while traveling, bringing the total number of approved units to eleven. The newly authorized devices are DeVilbiss Healthcare's **iGo**, International Biophysics Corporation's **LifeChoice**, Inogen's **Inogen One G2** and Oxlife's **Independence Oxygen Concentrator**.

Portable oxygen concentrators are small, portable devices that separate oxygen from nitrogen and other gases in the air and provide oxygen to users at greater than 90 percent concentration. They do not use compressed or liquid oxygen, which the government classifies as hazardous material. The Department of Transportation requires that U.S. carriers allow passengers to use portable oxygen concentrators approved by the FAA during all phases of a flight—including taxiing, take-off and landing—if the unit displays a manufacturer's label that indicates it meets FAA requirements for portable medical electronic devices, is properly stowed, and meets certain other applicable safety-related conditions.

For example, passengers must ensure the unit is in good working order and must be able to respond to the unit's warning alarms. They must protect extra batteries in carry-on baggage from short circuits and physical damage. Carriers also must let passengers operate these FAA-approved concentrators while moving about the cabin whenever the captain turns off the "Fasten Seat Belt" sign. Carriers can legally refuse to allow inflight use of an FAA-approved portable oxygen concentrator that does not have a manufacturer's label indicating that the device complies with FAA requirements. However, the Department encourages airlines to voluntarily allow the inflight use of such devices. Inflight use of an FAA-approved portable oxygen concentrator, whether labeled or not, poses no safety danger so long as carriage of the device is in accordance with instructions provided by the FAA.

The FAA previously approved these portable oxygen concentrators for use:

- DelphiMedical Systems RS-00400
- Invacare XPO2
- AirSep Lifestyle
- AirSep Freestyle
- Inogen One
- SeQual Eclipse
- Respironics EverGo

New Method of Gene Therapy May Halt Emphysema Progression

By Jennifer Warner, WebMD Health News

Reviewed by Louise Chang, MD

December 21, 2009 — A new type of gene therapy may help stop the progression of emphysema in young people who have an inherited form of the deadly disease. Researchers say previous attempts to correct the gene mutation that predisposes young people to emphysema have failed to achieve lasting results. But a new study shows a different approach that targets cells known as alveolar macrophages to deliver the gene therapy to the lungs of mice with this form of inherited emphysema was successful in treating the condition for two years.

Emphysema is a progressive lung disease that causes severe shortness of breath. There is no cure for the disease. People born with a genetic mutation that causes a deficiency in alpha-1 antitrypsin are predisposed to an early form of emphysema as well as cirrhosis of the liver. Researchers say this single gene defect makes the condition an ideal candidate for gene therapy, which would replace the defective gene with a normal one. But the problem until now has been finding the right cell in which to transfer the gene and deliver it to the lung.

In the study, published in *The Journal of Clinical Investigation*, researchers developed a system to target alveolar macrophage (AM) cells within the lungs of mice with alpha-1 antitrypsin deficiency. AM cells play a key role in the development of emphysema. The results showed a single treatment of the gene therapy successfully delivered healthy human alpha-1 antitrypsin genes to 70% of the AM cells in the mice.

"The lung macrophages carrying the therapeutic gene survived in the lungs' air sacks for the two-year lifetime of the treated mice," says researcher Darrell Kotton, MD, associate professor of medicine and pathology at the Boston University School of Medicine, in a news release. As a result, researchers say the symptoms and progression of emphysema in mice that received the gene therapy were significantly improved compared with untreated mice.

SOURCES: Wilson, A. The Journal of Clinical Investigation, Dec. 21, 2009, online edition. News release, Boston University Medical Center. ©2009 WebMD, LLC. All Rights Reserved.

Remember: Oxygen in Use Means Beware of Hazards

Home oxygen use increases oxygen levels in the air, causing fires to burn faster and hotter. Smoking is the leading cause of fires involving home oxygen use, but such fires can be fed by any flame or heat source, such as electric razors, candles or hair dryers. So beware of safety when there is oxygen in the home.

Alpha-1 Advocacy Alliance

"Our mission is to improve the health and well being of those affected by Alpha-1 through support to patients, educating healthcare professionals, and advancing public policy for the Alpha-1 Community."

Blood-oxygenating Device to Get Human Trials

by Steve Twedt and Michel Sauret, *Pittsburgh Post-Gazette*, January 5, 2010

Pete DeComo, chief executive officer, and Nick Kuhn, chief operating officer of ALung Technologies, show off their HemoLung respiratory-assist device that works as an artificial lung for medical patients. Mr. Kuhn expects to receive a phone call within the next few weeks that could signal big things for the small South Side company.

The call may come from the Artemis Health Institute in Gurgaon, India, or one of five hospitals in Germany where doctors are preparing to use ALung's Hemolung respiratory assist device on a human patient for the first time. If all goes well, ALung could be selling Hemolung to hospitals throughout Europe a year from now, and in the United States by late 2012.

The Hemolung does for patients with chronic respiratory problems what hemodialysis does for patients with kidney disease, intervening to support a patient through a possibly life-threatening infection without the need for a ventilator. Through a catheter inserted in either the femoral or jugular vein, Hemolung simultaneously extracts carbon dioxide and administers oxygen using a patented cylinder design with specially coated fibers that allow the gas exchange.

Functionally, it is the same idea as the highly specialized treatment known as Extracorporeal Membrane Oxygenation (ECMO), only its developers say Hemolung is safer, faster, more efficient and cheaper - and can be used at any hospital that is capable of doing dialysis. Where ECMO requires two large catheters, Hemolung has one small catheter, reducing the risk of an infection. With ECMO, 40 percent to 50 percent of the patient's blood may be circulating outside the body at any given minute, so the procedure requires close supervision; with Hemolung, it's 5 percent to 8 percent. Even if the machine completely shuts down unexpectedly, patients should not be in any immediate danger. Also, ECMO requires maintenance as frequently as every six hours to prevent clotting. Because of its design, Hemolung has gone eight days in animal trials without any clotting problems.

Currently, a ventilator can end up being the best option for someone with chronic obstructive pulmonary disorder who develops an infection and requires help breathing—patients who are “living on the edge,” said ALung Chairman and CEO Pete DeComo, a respiratory therapist by training who was director of respiratory care services at University of Pittsburgh Medical Center (UPMC) Shadyside from 1979 to 1985. But, while saving lives, ventilators can damage the lungs, are uncomfortable and leave a patient unable to talk or eat by mouth. Also, weaning a patient off a ventilator may take four to five days, while Mr. DeComo says a patient may be weaned from Hemolung in a matter of hours, all while allowing the patient to eat and talk.

The idea behind Hemolung emerged nine years ago from research being done at the University of Pittsburgh's artificial lung program. Actual work started on the first Hemolung prototype four years ago; the current incarnation is a 4-foot-tall, 150-pound machine with a cylinder seated with magnets on top that spins at 1,000 rpm. ALung has studied Hemolung's performance in sheep and pigs, leading up to the human trials. They're starting clinical trials in India and Europe first because the approval process is faster, said Mr. DeComo. They may get approval in Germany after studying Hemolung's effectiveness in only 20 patients, he said, which can lead to regulatory approval for all of Europe. In the United States, they expect it will take 200 patients and a year's time to gain approval from the Food and Drug Administration. The American clinical trials are expected to begin in early 2011.

But word is getting out here already, said Mr. Kuhn, and, “there's a lot of excitement” about using Hemolung as a bridge to keeping patients alive while they await a lung transplant—though that market is very small. The goal, he said, is to have Hemolung available at “every community hospital in the country.” They have designed Hemolung to use a catheter similar in size to those used in dialysis, so frontline clinicians will feel comfortable using it.

Shop at our Website



The Alpha-1 Advocacy Alliance Shoppe is located at <http://www.alpha1advocacy.org/frdonation.html>. While you are shopping for a T-shirt (design shown on the left), be sure to check out the other items

offered as fund-raisers. Also remember, when shopping online for ordinary items, be sure to go to the A1AA website and use the www.IGive.com and Giveline.com links to find those stores that give percentage (up to 25%) of your purchase dollars to your designated nonprofit organization. Also read about ordering magazine subscriptions through the A1AA website and save lots of money plus a possible free ticket for a movie.

Of course, our little buddy Alphapotamus can be purchased, too. Be sure to click on “full details here” and learn how Alphapotamus cheers up our little Alphas when they're in the hospital. Any purchase on the A1AA Shoppe site helps the Alpha-1 Advocacy Alliance continue to fulfill its mission “to advocate for all individuals affected by Alpha-1 Antitrypsin Deficiency (Alpha-1) through programs and services of personal advocacy, education, support and public policy in order to improve all aspects of their lives.”

If you're not a member of the A1AA, please join. To join, go to <http://www.alpha1advocacy.org/membership.html>. Thank you for your continued support and stay tuned for more announcements from the A1AA. It's a free membership and you'll get updates about A1AA programs, personal support, plus a copy of the bi-monthly newsletter.

My Transplant Story: Part 3—Rehabilitation

Ann Marie Benzinger

It was now two months since my wonderful transplant on April 23, 2009. I was still using a little oxygen (2 liters). The trache was removed without any pain or trauma and I could talk again normally. Moving around on my own was still not possible. My legs were very weak and I was using nursing help to stand up. I was still unable to walk to the bathroom. The coordinators had assured me that a week in a rehabilitation facility would have me going in no time. I wanted to believe them but something kept telling me there was no way I would be walking on my own in a week. The arrangements were made for me to move to the rehab center not too far from the hospital. I arrived by ambulance and was checked in late in the evening. I knew I was in trouble when the nurse came in with a weight scale and told me to get out of bed. I explained that I needed help only to be told, "Welcome to rehab, get up." After numerous attempts to pull myself just to a sitting position, she gave in and helped me up. This was only the beginning of rigorous workouts to get me back up and walking and providing for myself.



Occupational therapy showed up a 7 a.m. to help me bathe. This was my first bath/shower in two months and you can only imagine how good it felt to have hot water running over my head and back. I used a shower bench and extended shower arm and my therapist helped when my arm strength gave out and helped me dry off and get dressed. My therapist was like an angel with a soft and gentle kindness, understanding my need for slow, steadiness. In addition to helping me meet my personal needs, OT met with me a second time each day building on life skills. This included moving around a kitchen with the aid of a walker, learning to use a reaching stick to grab things up in the cabinets or that had fallen to the floor. At one point she taught me how to maneuver from the shower bench to the inside of the tub on my own.

Physical therapy was more grueling as we had to teach my muscles to work again. This meant daily stretching of my hamstrings and feet, truly painful when these muscles and ligaments haven't worked for months. I learned to walk with the guidance of parallel bars and then with a tall walker and graduating to a regular walker. I was slowly improving physically but I was once again suffering mentally from being gone from my family for so long.

While I was recovering, one of my daughters was undergoing chemotherapy and radiation for colorectal cancer discovered in February. My youngest daughter gave birth to her first child in June and I had yet to see her. My son had moved back into my home to maintain it and I was hearing reports of changes I wasn't ready to deal with. All I could think about was going home. The therapist concluded that I needed at least

three weeks of intense therapy which didn't make it easier but did give me a goal or endpoint to look forward to. There were high points in physical therapy when, for working my fine motor skills, I was allowed to play scrabble. I also had to raise balls on a rack and maneuver putty to work my fingers. Learning to climb stairs and gaining the strength to do it also was challenging. You don't realize how much muscle you need to just climb a stair until you can't do it.

In my last week of rehab I attempted to take a shower on my own. I walked towards the shower drain where there was a slight dip in the floor and bent over to pick up a towel. The next thing I knew I was on my back in pain on the floor, not knowing what to do. I was too far from the call bell and the bathroom door was almost shut so no one could hear my calls for help. In a short while an aid heard me and left for more help to get me up. Nothing was broken but my tailbone was bruised and hurt for quite a while.

The day I was released felt wonderful with the sun shining brightly. My sister and I stopped on the way home and ate lightly as my stomach still didn't feel up to par. Getting out of the car was difficult but with the help of my son and the walker I made it to my porch, only to fall as I attempted to climb the steps. Fortunately my son and his friend were able to lift me up and help me in the house. Simple things were not so simple anymore. I found I couldn't climb into my bed. It's an old bed and with one of the newer pillow top mattresses, it was too high for me to get my leg up into it. My sister had to literally shove me in the bed like a fish flopping up on a dock. The next day my brother graciously built me a step to make my bedroom livable again.

Home health care began the next day to check my vitals and do blood draws of my immunosuppression levels. While she was there my health seemed to deteriorate rapidly, as I just didn't feel right and then began to vomit blood. She called the transplant center and they sent me to the local transplant center for evaluation. I was given phenergan to stop the vomiting and had a rough reaction to it.

I began having muscle seizures that jerked my head, legs and arms every direction for seven hours. My body was exhausted by the time they stopped and I slept for a day. Blood work came back showing I had contracted CMV or cytomegalavirus, a virus dangerous to transplant recipients. My transplant center wanted me back in Maryland so arrangements were made for me to be transported back to the University of Maryland. My one day home had been a disaster and a disappointment and happiness all rolled into one.

Next Issue: Finally Going Home to Stay.

**Thank you for supporting Alphas
through the work of the
Alpha-1 Advocacy Alliance.**

Kamada Wins Brazilian Orders

Kamada Ltd. obtained marketing approval from Brazil's National Health Surveillance Agency (Anvisa) for its intravenous Alpha-1 Antitrypsin (AAT) protein for the treatment of congenital emphysema. Kanada announced in January that it has obtained export orders for AAT for the treatment of congenital emphysema and cystic fibrosis for patients lacking the AAT protein, type D emphysema, and to vaccinate against fetal hemolytic disease, a fatal blood disease. The orders for the company's emphysema treatment are worth NIS 15 million (1 Israeli shekel is about 25 cents) in 2010.

Bill Poplett Succumbs



Tuesday, February 16, 2010, the Alpha-1 community lost a fearless patient advocate, educator, mentor, and friend with the death of William (Bill) H. Poplett. Bill was a founding organizer of the Alpha-1 Advocacy Alliance, helping to form an organization dedicated to keeping the patient and their family at the forefront of support and

education. Bill reached out to each new Alpha he encountered, telling his story from diagnosis to transplant to showing his Chevy that he put so much time and love (and money!) into. Bill loved educating doctors and nurses about Alpha-1 and talking about organ donation. Ten years ago Bill received a single, right-lung transplant at Inova Hospital. This gift of life allowed him to witness his two girls' graduations, weddings, and the birth of his grandchildren. Bill leaves behind his wife, Betty; daughters Angie and Amy, sister Debbie Ehmen, brother Chuck Poplett and three wonderful grandsons. He will be greatly missed by all who knew him personally as well as all the internet connections he made and the friends he knew by telephone. The Alliance will miss his dedicated work and selfless donation of time to benefit all Alphas.

A1AA Memorial Scholarship

The Alpha-1 Advocacy Alliance Memorial Scholarship will once again be awarded this August to any Alpha continuing their formal education beyond high school. Those eligible may be children of Alphas regardless of phenotype.

This year we will award a minimum of two \$500.00 cash awards. To be eligible to win, entrants must submit a typed, 500 minimum, 1500 maximum paper on the following topic: How Alpha-1 Changed My Life.

The double-spaced paper typed in Microsoft Word, with the entrants Name, Address, Phone Number included on a cover page, may be emailed as an attachment to **scholarship@alpha1advocacy.org**. The paper also may be snail mailed to: A1AA PO BOX 202 Wolfstown, VA 22748.

Should you have any questions, please call 866-367-2122 9-5 EST.

Help Alhapotamus:

Find the words, which are forward, backwards, up, down, or diagonal.

BLAZE
BLAZER
BLIZZARD
BONANZA
BREEZE
BRONZE
BUZZ
BUZZARD
CITIZEN
CRAZY
DAZZLED
DENIZEN
DIZZY
DOZEN
DRIZZLE
EMBEZZLER
FIZZY
FRENZY
GAZELLE
GRAZE
HAZARD
HAZY
HORIZON
JAZZ
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PIZZA
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SNEEZE
SNOOZE
SQUEEZE
TOPAZ
TWEEZERS
WIZARD
ZANY
ZEAL
ZEBRA
ZENITH
ZEPPELIN
ZERO
ZEST
ZIPPER
ZODIAC
ZOMBIE

P B P D S D I S Z R E Z Z G M
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Q S L L E I A I U V O L Z A
H E I B W R Z R Z B R E E Z
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J E L L E Z A G U N M X P H
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B I F I Z O O R W F O P I E P
M T H A Z Y B I R R M D T E F
R I F I U E Z E E U Q S I I N
A C R R M A N Z X P I Z Z A J
R O Z A R Z D I Z Z Y Z A R C
H Q O D Y W J A T P Y N A Z X
J R K E M N O M B H Z A P O T



Solve the cryptogram—substitute letters to form a familiar phrase.

A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y	Z
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Safety Labeling Changes for Spiriva HandiHaler Approved By FDA

In December 2009, the Federal Drug Agency Center for Drug Evaluation and Research (CDER) approved new labeling for Spiriva HandiHaler (tiotropium bromide) inhalation powder. Basically use of this inhaler is contraindicated in patients with a hypersensitivity to ipratropium or tiotropium. In clinical trials and post-marketing experience with SPIRIVA HandiHaler, immediate hypersensitivity reactions, including angioedema (including swelling of the lips, tongue, or throat), itching, or rash have been reported.

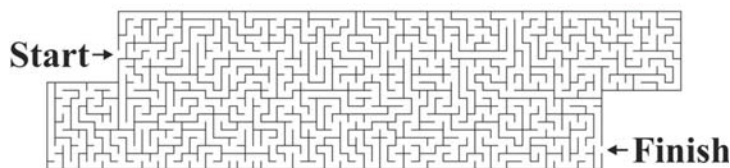
Given the similar structural formula of atropine to tiotropium, patients with a history of hypersensitivity reactions to atropine should be closely monitored for similar hypersensitivity reactions to Spiriva HandiHaler. In addition, Spiriva HandiHaler should be used with caution in patients with severe hypersensitivity to milk proteins.

Spiriva HandiHaler should be used with caution in patients with narrow-angle glaucoma. Prescribers and patients should be alert for signs and symptoms of acute narrow-angle glaucoma (e.g., eye pain or discomfort, blurred vision, visual halos or colored images in association with red eyes from conjunctival congestion and corneal edema).

Spiriva HandiHaler should be used with caution in patients with urinary retention. Prescribers and patients should be alert for signs and symptoms of prostatic hyperplasia or bladder-neck obstruction (e.g., difficulty passing urine, painful urination). Instruct patients to consult a physician immediately should any of these signs or symptoms develop.

There are no adequate and well-controlled studies in pregnant women. Spiriva HandiHaler should be used during pregnancy only if the potential benefit justifies the potential risk to the fetus.

Can you find the way to the finish?



	Organ/Tissue Donor Card	
I wish to donate my organs and tissues. I wish to give:		
<input type="checkbox"/> any needed organs and tissues	<input type="checkbox"/> only the following organs and tissues:	
Donor Signature _____	Date _____	
Witness _____		
Witness _____		

Cluster Headache and Alpha-1 Antitrypsin Deficiency

Little is known about the pathophysiology of cluster headache (CH), one of the most debilitating primary headaches. Interestingly, associations of lung-affecting diseases or lifestyle habits (such as smoking and sleep apnea syndrome) and CH have been described. Certain genotypes for alpha-1 antitrypsin (A1AT) are considered risk factors for emphysema. The aim of a study conducted by Oliver Summ MD et al. was to investigate possible associations between common genotypes of the SERPINA1 gene and CH. It included 55 CH patients and 55 controls. A1AT levels in serum and the genotype were analyzed and the patients' CH characteristics were documented. They could not detect any association between CH and a genotype that does not match the homozygous wild type for alpha-1. Interestingly, there is a significant difference of CH attack frequency in patients who are heterozygous or homozygous M allele carriers. They concluded that the presence of an S or Z allele is associated with higher attack frequency in CH.

Source: O. Summ, N. Gregor, M. Marziniak, I. Gralow, I. W. Husstedt, and S. Evers, *Cephalalgia*, Vol. 30, No. 1, 113-117 (2010)

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“Tidal Wave”—Number of People with Diabetes Will Double

by Elinor Nuxoll

As an advocacy member of the Alpha-1 Lungs & Life group, I often answer inquiries about diabetes. It is a chronic disease that affects millions of people including some Alphas and members of their families. In a way it affects all of us because of rising health care costs.

As the U.S. population ages and grows more overweight, there will be a “tidal wave” of Americans with diabetes, according to Michael O’Grady, co-author of a new study. The December 2009 issue of *Diabetes Care* published a University of Chicago report which predicts that the number of people with diabetes will nearly double in the next 25 years, to 44 million, and annual spending will triple to \$336 billion.

Baby boomers are aging and they tend to be heavier. Type 2 Diabetes is linked to obesity. Weight control is the key to reducing the risk of getting diabetes. Lifestyle changes can prevent it or prevent complications like kidney disease, heart attack and blindness.

Health screening is widely available and diabetes can be diagnosed by a simple finger prick blood test. When I was first diagnosed, my doctor prescribed pills to control my blood glucose, that is, blood sugar. Two years later I had gained weight and I had a heart attack. When I left the hospital I started six months of cardiac rehabilitation and aerobic exercise. I lost the weight I had gained but still needed the pills to control my blood sugar levels.

My change to insulin shots came as a result of taking Prednisone which my doctor had prescribed for the pain of polymyalgia. It played havoc with my blood sugars. When mine zoomed to 499, I was admitted to the hospital and started on insulin.

I had always tried to control diabetes by diet. Instructions from the hospital advised three daily meals with food from the following food groups:

- Bread - bread, cereal, potatoes, rice, beans
- Meat - Fish, poultry, cheese, eggs, peanut butter
- Vegetables - Salads, broccoli, carrots, green beans, etc.
- Fruits - Apples, oranges, bananas, berries, melon, etc.
- Dairy - Low fat milk, yogurt, cottage cheese
- Avoid foods that cause a rapid increase in blood sugar and have little nutritional value such as soft drinks, soda, sugar, honey jam, jelly, or candy; have meals at the same time each day.

I learned from my Alpha friend that it is best to have smaller meals and have snacks between meals. He ate six times a day, sometimes just a slice of peanut butter toast. I live in assisted living so my meals are prepared for me, but I buy fruit and nuts for snacks. We can choose alternates instead of the regular menu. I don’t eat beef or pork. I avoid fried foods and I ask for low carbohydrates, small servings of pasta,



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ARALAST NP is indicated for chronic augmentation therapy in patients having congenital deficiency of A₁-PI with clinically evident emphysema. ARALAST NP is not indicated as therapy for lung disease patients in whom congenital A₁-PI deficiency has not been established.

Important Safety Information
ARALAST NP is contraindicated in individuals with significant high cholesterol (HDL level less than 15 mg/dL) who have known antibody against IgA, since they may experience severe reactions, including anaphylaxis to IgA, which may be present in small quantities in the blood during product use.
ARALAST NP is derived from pooled human plasma. It may carry a risk of transmitting infectious agents, e.g., viruses and theoretically, the Creutzfeldt-Jakob disease (CJD) agent.
The most common adverse events observed related to ARALAST NP included: headache (4 of 61 [7%] events) and maculopapular dermatitis (4 of 61 [7%] events).

Trade Name: ARALAST NP, an AbbVie Inc. product. © 2010 AbbVie Inc. All rights reserved. 09/10/09-000000

potatoes or rice. They serve white rice; obviously brown rice, wild rice or quinoa would be much better. I avoid salty foods like chips and I choose fresh fruit rather than sweet desserts.

Because diabetes is so common there is an abundance of information available. There are books, magazines, websites and free e-newsletters. Many tasty recipes are easy to find. I am always learning something new. Diabetes runs in families. If there are diabetics in your family, it should be part of your health history.

I would like to hear from Alphas who have questions about nutrition, whether or not diabetes is involved. With Alphas, obesity is often not a problem. My friend was underweight and had a difficult time trying to gain minimum weight to be put on the transplant list.

IGIVE.com



iGive.com is an Internet organization that allows you to designate your favorite charity as the beneficiary of your online shopping. The Alpha-1 Advocacy Alliance is one such charity that benefits. Over seven

hundred (700+) member stores donate a percentage, ranging from 1% to 26%, of what you spend with them. This can add up to sizable donations for our group. You probably already shop at some of the stores, such as Lands’ End, JCPenney, Office Depot, Amazon, and Staples.

Getting Your Medical Records

While there are no statistics on how many patients have trouble accessing their own records, there have been “repeated” complaints to the Department of Health and Human Services, according to a senior health information privacy specialist at the department’s Office for Civil Rights, which enforces the federal law that gives patients access to their records. Despite a federal law requiring hospitals and doctors to release medical records to patients who ask for them, patients are reporting they have a hard time accessing them. To make sure you get your medical records, follow these tips:

1. Know your rights. The federal *Health Insurance Portability and Accountability Act*, which governs access to medical records, gives hospitals and doctors 30 days to respond to a request for medical records, although some state laws provide for a shorter time frame and, in urgent situations (such as a transfer to another hospital) it’s customary for hospitals to move more quickly. Be prepared to make your request in writing. You can bring it in person or fax the request in, but make sure you confirm that the hospital has received it. One way to get your medical records more quickly is to seek out providers who use electronic medical records so the records can be e-mailed to you. Some providers have an electronic portal so you can read your records anytime you want on a secure site on the Internet.
2. Get the new hospital or doctor to help you. If you need your records because you’re switching hospitals or doctors, ask the new office to make the records request, it’s probably going to be faster.
3. Remember the limits of the law. Your doctor doesn’t have to give you access to everything in your record. For example, your doctor doesn’t have to give you access to information he or she thinks might cause you or someone else substantial harm, says the senior health information privacy specialist at the Department of Health and Human Services. Some states allow even more information to be kept from a patient. For example, the New York Department of Health Web site says doctors may deny you access to “personal notes and observations” they’ve made in your record.
4. Get angry. Sadly, you might have to get angry in order to gain access to your medical records. Don’t let them tell you no. It’s your data.

5. File a complaint. If you have trouble getting access, you can file a complaint with the Office of Civil Rights at the U.S. Department of Health and Human Services. For more information, go to their web site at <http://www.hhs.gov/ocr/office/file/index.html>.

Information about Liver Blood Tests

An initial step in detecting liver damage is a simple blood test to determine the presence of certain liver enzymes in the blood. Among the most sensitive and widely used of these liver enzymes are the aminotransferases. They include aspartate aminotransferase (AST or SGOT) and alanine aminotransferase (ALT or SGPT). These enzymes are normally contained within liver cells. If the liver is injured, however, the liver cells spill the enzymes into blood, raising the enzyme levels in the blood and signaling the liver damage. Read more about these tests at <http://mybeautycarelab.blogspot.com/2010/02/information-about-liver-blood-tests.html>

Stem Cell Therapy for COPD

According to the COPD Foundation, there are 24 million cases of COPD in the United States and one COPD patient dies every 4 minutes. Now a biomedical company offers hope for a cure. Entest Biomedical Inc, a subsidiary of Bio-Matrix Scientific Group Inc, has begun studies of the company’s stem cell/laser regenerative therapy for COPD. According to an announcement, Entest has begun investigations into the effects of low energy near infrared radiation on cultured cells as a first step toward animal preclinical studies for the treatment of the disease. The focus of these investigations, which are an extension of current Entest intellectual property covering an enhancement of stem cell growth and activity, will be on type II alveolar epithelial cells and related stem cells that reside in the lung.

“Wii” Can Enhance the Effects of Pulmonary Rehabilitation

Not only Wii “Fit,” but also Wii “Sport,” could be enjoyable ways to “use it” and not “lose it.” The use of Wii technology could provide pulmonary rehabilitation programs with the extra factor needed to **keep** patients motivated in the long term. Being asked to follow an exercise program using Wii is no doubt more enticing than following exercise instructions provided on paper. Plus exercising with Wii can get the whole family involved in the process and make exercise more fun and less of a chore. Of course there are financial and safety issues associated with this. However, the use of Wii in the rehabilitation of patients following a stroke and in children with cerebral palsy is gaining momentum. So, perhaps for some patients “Wii” can enhance their experience of pulmonary rehabilitation.

Phone Home on Us

To sign up for the program cosponsored by A1AA and Coram Healthcare, go to

http://www.alpha1advocacy.org/a1aa_phonocard_program.htm

or call us toll free at 1-866-367-2122.



Alpha-1 Advocacy Alliance
PO Box 202
Wolftown, VA 22748

Address Service Requested

FOR INFO CALL: 540-948-6777
Toll Free: 1-866-FOR-A1AA
Fax #: 540-948-6763
<http://www.alpha1advocacy.org>

Inside: My Transplant Story: Part 3—Rehabilitation

THE ALPHA-1 FAMILY PROVIDING INFORMATION AND EDUCATION TO THE COMMUNITY.

Alphapotamus—Remembering Ask Pat

On Sunday December 27, 2009, the Alpha-1 Advocacy Alliance community lost a very special member of our organization, Patricia Ann Slavin, also known as Ask Pat. Pat was a remarkable woman who participated in her Alpha-1 community right from the beginning by becoming part of the clinical trials for Prolastin. In 1992, she received a single-lung transplant at the University of Virginia in Charlottesville, VA and enjoyed the benefits of her renewed gift of life for seventeen and one-half years with barely a cold until this last year. After her first year post transplant, Pat decided to return to college and graduated in 2000 from Virginia Commonwealth University with a Masters Degree in Social Work.

Pat entered the workforce in the social services field and loved helping others reach beyond for their full potential, working through their roadblocks and counseling them through their life changes and challenges. Through her experiences, I saw the potential to reach out to other Alphas and develop the *Ask Pat* program. Pat developed the themes and wrote the programs and then went “on air” during our weekly and then monthly counseling times for five years. Pat was willing to discuss anything and nothing was embarrassing if it concerned you. One of her favorite topics was dealing with denial of the family, both immediate and distant, who didn’t want to face the realities of Alpha-1 in the lives of their loved ones.

Pat had grace and patience and always helped you find your own answers. She would lead you to the water, but you would drink from her fountain of information and know you were strong enough to handle the problem at hand when your conversation was finished. She was a leader and a friend. She will be greatly missed.

The family suggests donations in her honor be made to the American Lung Association, 9221 Forest Hill Avenue, Richmond, VA 23235.



*Hi
to All our
Little Alphas!*