



NHOPA NEWS

National Home Oxygen Patients Association

Volume 10, Number 8

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Annual membership dues renewal notices have been mailed out. Send in your renewal dues now and don't miss out on a single issue of NHOPA News!

ANNUAL NHOPA MEETING

The annual NHOPA Meeting is scheduled for **November 14, 2007 at 11 am Eastern Time** via Conference Call. This meeting is just around the corner and we would like YOU to participate. To register for participation or if there are agenda items you would like the Board to discuss, please notify the Executive Office no later than November 1 via fax at 703-752-4360, by email at ExecOffice@homeoxygen.org or by phone a 1-888-646-7244. Registered members will be provided with a toll free phone number and access code prior to November 14, 2007.

Come join us and see what NHOPA is doing for YOU!

Alpha-1 Antitrypsin

Alpha-1 antitrypsin deficiency, also known as AATD or Alpha-1, is a genetic condition that is inherited by children from their parents. AATD may result in severe lung and/or liver disease at various ages. Because it leads to the destruction of lung tissue it may often be misdiagnosed as asthma or COPD.

A protein, alpha-1 antitrypsin (AAT) typically protects the lungs from inflammation caused by infections or inhaled irritants. AAT is usually made by the liver and released into the bloodstream. With AATD the body, due to a genetic abnormality, has little or no AAT in the bloodstream because it is not released from the liver normally. This leads to an abnormal build up of AAT in the liver causing liver disease. Reduced levels of AAT in the blood can result in lung damage and possibly lung disease putting one at risk of emphysema.

Three in four adults with a severe AAT deficiency will get emphysema, some when they are younger than 40. Smoking increases this risk. Children with AAT deficiency can develop liver problems that last their entire lives.

To provide an insight as to what happens genetically with AATD the Alpha-1 website states "For each trait a person inherits, there

are usually two genes and one gene comes from each parent. People with Alpha-1 have received two defective alpha-1 antitrypsin genes. One defective gene came from their mother and one from their father. There are many types of defective alpha-1 antitrypsin genes. The most common abnormal genes are called S and Z. Normal genes are called M. A person who does not have Alpha-1 will have two M genes (MM). People identified with Alpha-1 most commonly have two Z genes (ZZ). Current evidence suggests there are up to 100,000 people with Alpha-1 (ZZ) in the United States. Another deficient gene combination is SZ, although people with this gene combination are less likely to get lung or liver problems than those with two Z genes." Statistics show that an estimated 20 million people have one normal and one defective AAT gene. Genetic combinations in people with one normal and one defective gene (for example MZ) are termed "carriers". Carriers may pass on the defective gene to their children.

Alpha-1 spans the population having been identified in virtually all populations and ethnic groups. Estimates are that as many as 1 in every 2,500 Americans have Alpha-1.

Identification and diagnosis of AATD is made via a physician ordered blood test. If one family

member is found to have AATD, other family members should also take the blood test.

Currently AATD can be treated but not cured. One treatment involves adding to or replacing the missing protein. If seriously ill, a lung transplant may be an option. Staying away from cigarette smoke is crucial.

Early diagnosis is key. The Medical University of South Carolina (MUSC), with support of the Alpha-1 Foundation, has developed a free and confidential opportunity for testing. This testing is done through a research study called the Alpha-1 Coded Testing (ACT) Study. The Alpha-1 Research Registry was also established by the Alpha-1 Foundation. The Registry, a confidential database composed of persons diagnosed with Alpha-1 (AATD) and those identified as carriers, facilitate research initiatives and promote the development of improved treatments and a cure for Alpha-1.

Information for this article was obtained from the Alpha-1 Foundation (www.alphaone.org) and Medline Plus (www.nlm.nih.gov/medlineplus). For detailed information visit these sites.

POC Regulations Moving Forward

Key members of Congress sent a letter to the U.S. Department of Transportation (DOT) asking them to issue final regulations governing the use of portable oxygen concentrators (POCs) on commercial airlines.

DOT Secretary Mary E. Peters responded by

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The National Home Oxygen Patients Association is devoted exclusively to improving the lives of people across the country who require supplementary oxygen on a regular basis.

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stating that the regulations are being finalized and should be ready by year end. At present the federal government gives the airlines the *option* to permit approved POCs on board. Proposed regulations, if enacted, would *require* the airlines to allow POCs onboard.

Secretary Peters stated "I fully appreciate your concern about the difficulties encountered in air travel by users of medical oxygen," and "I am committed to providing individuals dependent on medical oxygen greater access to air travel, consistent with Federal safety and security requirements."

The letter was sent by Senator Blanche Lincoln (D-AR), Senator Mike Crapo (R-ID), Congressman John Lewis (D-GA), and Congressmen Cliff Stearns (R-FL), all key members of the Congressional COPD Caucus.

Information was obtained in part from the American Association for Respiratory Care website (www.aarc.org).

ALA and the Respiratory Health Association of Metropolitan Chicago

NHOPA recently received a communication from Kristen Donnelly regarding the organization that was known as the American Lung Association (ALA) of Metropolitan Chicago. This organization has changed its name as of July 1, 2007 to Respiratory Health Association of Metropolitan Chicago (RHAMC) and is no longer affiliated with the ALA.

In a letter to NHOPA, RHAMC CEO Joel Africk and Board Chair Douglas Graham stated that RHAMC's mission is very similar; it remains to "promote healthy lungs and fight lung disease".

The letter explains the reasons behind the breakaway as the following: "Our decision comes as the American Lung Association's National office is regionalizing many of its local offices into large multi-state regions. In response, our Board has joined a number of local chapters around the country who are choosing to begin operating independently of the national organization, rather than sacrificing their strong ties to their communities and their deep understanding of local issues. We believe our mission is best served as an independent organization directly addressing local lung health needs."

RHAMC's location, staff, programs and contact information remain largely the same. For more

detailed information see their website at www.lungchicago.org.

For more information on your local ALA chapter, contact them directly. Contact information can be obtained from the ALA website at www.lungusa.org.

Thanks to Kristen Donnelly of Respiratory Health Association of Metropolitan Chicago (www.lungchicago.org) for communicating this important information to NHOPA.

Questions & Comments

Roxlyn Cole sent us the following inspirational story on her half marathon at high altitude with oxygen. "I pushed my baby jogger stroller holding four high flow oxygen tanks and a back-up compressed gas cylinder to complete the HIGHEST Half Marathon in the entire USA. (<http://www.slackerhalfmarathon.com>) It began in the parking lot of Loveland Ski basin right near the Eisenhower tunnel with views of the Continental Divide. We climbed from an altitude of 10,600 ft up to 10,880 ft then down to 8500 ft finishing in Georgetown Colorado. The first 5 miles were on rocky trail then paved for the remaining 8.1 miles for a 13.1 mile total.

[My partner, Mike, pulling his 4 liquid tanks on a pull cart, and myself] both required 15 L/min. Mike uses a cannula while I was "necking with oxygen" using 12 L/min through a TTO SCOOP [catheter] and another 3 via cannula. For the uphill parts, maybe a mile worth we did have to turn the flow higher; it was difficult but downhill...ouch that hurts after hours of walking!

[Our final time of] 4 hrs and 58 seconds isn't too accurate as that is from the official start. We were waaayyyy back behind hundreds of runners...oh, and ahead of two, we were not last place. Two gals received the dubious distinction of being this years "slackers". Other half marathons I have completed as low as 3 hrs 36 minutes. Guess the rough and rocky trail took its toll!

We have all the fun of a competitive event...and none of the pressure to win...only win against our own personal bests. I hope if they really get more early diagnosis and athletic types get "it", they will see one can still keep moving and have some fun...even at age 69 and 53..."

Roxlyn you Rock! Congratulations on your high altitude feat! Roxlyn finished 6th overall in the Female Age Group 60-69.

Judith Winter wrote "I have heard conflicting advice about cannulas with [the Respironics] EverGo [portable oxygen concentrator (POC)]. Both MUST and DON'T use high-flow cannula, when using high settings. What's true? Also, I have a face-mask, which [my doctor] had suggested I use for high-flow (home use, prior to discussing POC). Should I be prepared to use or bring it with me? I called [the manufacturer of] EverGo. They said [to use a] 'regular cannula' only, which they provide with machine.'

The EverGo unit, manufactured by Respironics is the latest addition to the FAA approved POCs. This pulse dose unit has settings from 1 to 6 in .5 increments. Checking the website of the EverGo (www.respironics.com), specifically the Frequently Asked Questions section, there is a question "What type of cannula works with EverGo?" The response the manufacturer gives is "A standard single-lumen nasal cannula and tubing (not supplied) should be used to deliver oxygen from EverGo. The device works with cannula tubing up to 30 ft. (9.1 m). A standard nasal cannula that can be provided by your oxygen provider should be sufficient as long as you have been tested on the POC for adequate saturations at rest, exercise, walking and sleep if you plan on using it during the night."

The standard single-lumen cannula is typically what is dispensed with most types of oxygen systems (liquid, cylinder, concentrator, and POCs) and these can be obtained from your homecare provider. There are a few systems, such as the HELIOS portable oxygen system, that use a dual lumen cannula. A dual lumen cannula connects to two separate ports on the portable unit; one port/lumen of the cannula senses the user's inhalation and the other port/lumen delivers the oxygen. If you are unsure which type your specific unit uses ask your oxygen provider.

Regarding the use of a face mask, typically this type of oxygen delivery device requires a minimum flow of 6 L/min to keep the device flushed of any exhaled CO₂. Talk with your physician regarding your current needs.

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New Products

The following information on new products/companies available on the market is for informational purposes only. NHOPA does not specifically endorse ANY products. Contact your physician for further information regarding your healthcare or the specific company for product information.

A new long acting bronchodilator that is currently available as a dry power inhaler by Dey L.P. in the US, will soon be available as a nebulizer solution. The medication, currently known as Foradil® (formoterol fumarate) in dry powder form, is in Phase III clinical trials as a nebulizer solution and will be called **Perforomist Inhalation Solution®**. Perforomist has received FDA approval for a New Drug Application.

Chad Therapeutics Inc. has released two new oxygen transfilling devices – the **OMNI-2™** and the **OMNI-5™**. These devices are available with seven cylinder sizes and are compatible with more than 20 CHAD oxygen conserving devices. The OMNI-2™ is designed for pediatric patients. The OMNI-5™ offers features which include stationary oxygen flows up to 5 L/min and an automatic restart upgrade on the cylinder transfilling process. For more information call 800-423-8870 or visit www.chadtherapeutics.com.

I Didn't Know That.....

(received via email – anonymous)

Q: Why do men's clothes have buttons on the right while women's clothes have buttons on the left?

A: When buttons were invented, they were very expensive and worn primarily by the rich.

Because wealthy women were dressed by maids, dressmakers put the buttons on the maid's right. Since most people are right-handed, it is easier to push buttons on the right through holes on the left. And that's where women's buttons have remained since.

Q: Why do X's at the end of a letter signify kisses?

A: In the Middle Ages, when many people were unable to read or write, documents were often signed using an X. Kissing the X represented an oath to fulfill obligations specified in the document. The X and the kiss eventually became synonymous.

Q: Why is shifting responsibility to someone else called "passing the buck"?

A: In card games, it was once customary to pass an item, called a buck, from player to player to indicate whose turn it was to deal. If a player did not wish to assume the responsibility, he would "pass the buck" to the next player.

Q: Why do people clink their glasses before drinking a toast?

A: It used to be common for someone to try to kill an enemy by offering him a poisoned drink. To prove to a guest that a drink was safe, it became customary for a guest to pour a small amount of his drink into the glass of the host. Both men would drink it simultaneously. When a guest trusted his host, he would then just touch or clink the host's glass with his own.

◆ For up-to-date information and membership applications go to www.homeoxygen.org ◆