



NHOPA NEWS

National Home Oxygen Patients Association

Volume 10, Number 4

May 2007

COPD Foundation & COPD Research

This information was obtained from the COPD Foundation website.

New therapies, better protocols and possibly even a cure for COPD are goals the COPD Foundation is spearheading research to find. Toward that end the COPD Foundation is gearing up a research registry to promote COPD research and help patients identify and evaluate research opportunities.

The COPD Foundation Research Registry is a confidential database of individuals diagnosed with Chronic Obstructive Pulmonary Disease (COPD). The COPD Foundation is working with National Jewish Medical & Research Center in Denver, Colorado to host the database and ensure the strictest confidentiality of patient information. No researchers or any other third party personnel will have access to personal information (such as names, addresses) without the patient's prior knowledge and consent.

Enrolling in the Registry is easy. Go to www.copdfoundation.org/Registry/. Complete and submit the Registry survey. Once enrolled, the COPD Foundation Registry will send invitations to participate in COPD research, including clinical trials for new therapies. There is also an option on the website for downloading a paper copy of the form and mailing it to the Registry for enrollment.

The first study the Registry is undertaking is to find out what makes some people more likely to develop COPD. For this study the Registry will also need individuals that have smoked but have not develop COPD. This way they can compare the two groups to find differences.

For more details and to register visit <http://www.copdfoundation.org/Registry/>. Contact them directly at (866) 316-COPD (2673)

FDA Warning for Xolair

The FDA has requested Genentech, Inc., manufacturer of Xolair, add a box warning to Xolair that it may cause anaphylaxis and to provide a medication guide for patients to strengthen the existing warning for anaphylaxis. Xolair is given via subcutaneous injection. Xolair is the first IgE blocker developed to treat the symptoms of asthma related to allergies.

Questions & Comments

This was received via email: "My dad is a NHOPA member. An article ran last month concerning traveling with the Inogen One concentrator. We bought one so we could start traveling again. He has used it for 1 week now constantly. I noticed last night he was showing signs of lack of oxygen. He had not gotten out of bed all day. He said things that did not make sense. He sounded a bit incoherent. I put him back on his normal machine and after a couple hours he seemed a bit better. I was hoping the Inogen One would last at least 1 week so we could take a cruise. Do you know of people that have used this for that long?"

Thanks for your email. There are a number of reasons that may be attributed to your dad's symptoms, one of which could be inadequate oxygen levels. If the symptoms are attributed to low oxygen levels they may or may not be related to the use of the portable oxygen concentrator (POC).

One explanation for inadequate oxygen levels is the way oxygen is delivered. The Inogen One is a pulse dose delivery system which means that oxygen is delivered only during the initial portion of inspiration. Continuous flow oxygen is delivered throughout the entire phase of inspiration and expiration.

When switching from continuous flow to pulse dose delivery a patient should be tested with a pulse oximeter by their physician to make sure

that they are able to maintain adequate oxygen saturations with the pulse dose unit at rest and with exercise. Some people are unable to maintain adequate oxygen saturations with pulse dose. A change to pulse dose requires a new prescription from your doctor.

There are 5 POCs currently available for travel. Four of the five are strictly pulse dose delivery while the fifth unit, the SeQual Eclipse, has the capability of providing continuous flow (1 to 3 L/min) as well as pulse dose delivery. (See the Dec 06/Jan 07 newsletter for a detailed comparison chart on POCs)

As a reminder, whenever you or a family member is experiencing changes in medical condition, you should seek medical assistance immediately.

Thanks for a good question!

POCs as a Primary Source

Jon Tiger wrote regarding the March Newsletter "In response to a question from Kathy Nicholson you stated, "one point to consider is that the POCs are not necessarily built for extended use such as your home fill system." Some suppliers are providing a POC as a primary O2 source. And, I know several users who are in the process of securing a POC as their primary source."

Jon thanks for the feedback. You are correct that the POCs can be used as a primary source for oxygen delivery. One caution: make sure that a backup oxygen supply is available (such as an

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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.

Publication of the NHOPA monthly newsletter is made possible through a generous grant from the American Association for Homecare.

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E-tank) in the event of a power failure, unit malfunction or the POC does not have enough battery charge.

"Nose Hose" Alternative

Bob Mogue, Director of Home Care for Southmedic, wrote to remind us that "There are other options to "nose hoses" which the NHOPA News readers should be made aware. One of those options is the family of OxyArm products offered by Southmedic. Information about these products may be found on their website www.southmedic.com."

Bob thanks for the reminder. In a previous newsletter the OxyArm™, an alternate to the nasal cannula, was previewed. The OxyArm™ is a minimal contact, open oxygen delivery device. The device has a unique headset design and a baffled cup delivery system which offers controlled delivery of variable oxygen concentrations in a comfortable and unencumbered way. The system is latex free and odorless. Southmedic also provides an alternative to the oxygen mask. For more information and pictures check out their website at <http://www.southmedic.com>.

Travel Feedback

James Bagley faxed us with the following "I wanted to share with you an experience that I had last week. My wife called United Airlines for arrangements to utilize an Inogen One on a flight to and from Washington, D.C.

We were advised that United Airlines did not allow the use of this equipment on their flights. The only recourse we had was to use their oxygen at \$100.00 per segment. I have a list of airlines allowing the use of this equipment and it is quite long.

Have you heard of this happening? We are part of a group and cannot change airlines at this point so must use their oxygen, which makes me very unhappy. I think this information about United should be shared so if you have choices don't use United. They were also not very polite or helpful probably because they were not familiar with the Inogen One."

*Thank you for your letter James. United is the only large carrier that does **not** permit the use of the POCs on board their aircrafts. This information has been published in previous*

newsletters but currently the best place to obtain information regarding which airlines accept POCs is the NHOPA website. This information can be found by navigating to the NHOPA website at www.homeoxygen.org and clicking "Airline Oxygen Policy". Other current information is available on the new website.

Remember that the Inogen One can be used during layovers that you may encounter. We hope that this assists you in future travel.

Bob Kern wrote to us of his flying experiences with the POCs. "My home oxygen supplier provided me with a portable Inogen One concentrator, an Invacare stationary concentrator, an Invacare refill unit, two portable tanks [which last six hour each for me], a large reserve tank, cannulas, etc.

In Sept we made a trip via auto to New England from Virginia. The small tanks were convenient for walking around. The Inogen One was used when sleeping.

During December/January I flew from Washington, DC, to Moscow, Russia, via Aeroflot Russian Airlines with my Inogen One. I had asked Aeroflot about it when I bought the ticket. They assured me that there would be no problem. There wasn't.

While in Moscow I joined a Russian tour group to Israel. We flew on Transareo. I didn't ask permission in advance. Again there was no trouble.

I had no trouble getting through the security checkpoints at Washington/Dulles, New York/Kennedy, Moscow/Sheremetrevo, Moscow/Domodovidnovo, or Tel Aviv/Ben Gurioin. I carried with me a list of my medications and medical devices on my MD's letterhead and signed by him, but only at Dulles did they even bother to look at it."

The only problem that I noted is the 10 pound portable got a little heavy either in its satchel or on its cart.

The last I heard there are now four manufacturers of portables. Anybody interested should contact each and check the specifications of their units; they all differ."

Bob thanks for your feedback on your travel experience. Currently, there are four

manufacturers of the five POCs approved for air travel, Inogen One, AirSep Freestyle, AirSep Lifestyle, Respironics EverGo and SeQual Eclipse. The Respironics Evergo, has not been released as of this printing but is scheduled for release in the near future.

The Dec 06/Jan 07 newsletter provided a POC comparison chart with detailed information on the 5 POCs available for travel.

The NHOPA website also has information available regarding the POCs and a partial listing of providers where they can be rented for travel. Go to www.homeoxygen.org and click "POC Information".

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.

Are you Looking for a getaway this summer? Check out **Sea Puffer Cruises** at <http://www.seapuffers.com/>. Sea Puffer cruises offer oxygen users the support needed to travel with oxygen. Cruising with oxygen is a wonderful way to get out and see the world! Once settled in the cabin there is no more packing and unpacking until the day you leave! Friends and family are welcome to travel with Sea Puffers. Flying with oxygen is arranged by Sea Puffers as well. Where possible they try to use direct flights. Sea Puffer Cruises can be contacted directly at 1-877-473-2726.

A physical therapist in California recently designed an oxygen line system to offer an alternative to traditional nasal cannula delivery systems that drape over the ears. The **Oxy-Flex Nasal Cannula™** posterior oxygen line is adjustable, does not rest on top of the ears, and falls down the back of the head. It also features an easy to use adjustable clip at the crown of the head that the wearers may fit as loose or as snug as they please.

Information and pictures are available at <http://oxy-flex.net> or contact them by phone at 805.286.8317.

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Annual membership dues renewal notices have been mailed out. Make sure that you renew early so you don't miss out on an issue of NHOPA News!

- Dan Davis, an oxygen user and NHOPA member, has published a booklet *Stress-free Travel: 99 Secrets and Tips* which has several handy tips for travelers. The author is in the process of updating the booklet to include travel with oxygen. The cost for the current booklet is \$6.95. You can check this out and order at www.stress-freetravel.com.

The amazing golf ball

Source: Aha! Jokes, <http://www.AhaJokes.com/>

A golfer, playing a round by himself, is about to tee off, and a greasy little salesman runs up to him, and yells, "Wait! Before you tee off, I have something really amazing to show you!"

The golfer, annoyed, says, "What is it?"

"It's a special golf ball," says the salesman. "You can never lose it!"

"Whattaya mean," scoffs the golfer, "you can never lose it? What if you hit it into the water?"

"No problem," says the salesman. "It floats, and it detects where the shore is, and spins towards it."

"Well, what if you hit it into the woods?"

"Easy," says the salesman. "It emits a beeping sound, and you can find it with your eyes closed."

"Okay," says the golfer, impressed. "But what if your round goes late and it gets dark?"

"No problem, sir, this golf ball glows in the dark! I'm telling you, you can never lose this golf ball!"

The golfer buys it at once. "Just one question," he says to the salesman. "Where did you get it?"

"I found it."