



NHOPA NEWS

National Home Oxygen Patients Association

Volume 10, Number 11

December 2007

Annual NHOPA Business Meeting Election Results & President's Report

The annual NHOPA Business meeting was held November 14 at 11 am ET via conference call. NHOPA thanks all those that took time to join in the call and provide feedback.

Election Results

Executive Committee:

Jon Tiger – President
Robert Keith – Vice President
Secretary/Treasurer – Vacant

Board of Director User Members:

Sol Gould
Sally Everhart
Holly Lockwood
Carole Merkle
Suzanne Prinz
Jerome Doherty
William Anderson

Board of Directors – Non-User Members:

Kent Christopher, MD
Tom Petty, MD
Joe Petrolla – Seeley Medical
Mary Erslon – Covidien
John Frank – Respironics
Tom Ryan – American Assoc of Homecare
Stephanie Diehl, RRT – Newsletter Editor

Executive Office:

Phil Porte – Executive Director
Juliet Hedge-Ellis – Member Services
Karen Lui – Government Affairs

Appointed Position:

Tom Williams, VP of Development

President's Report

Jon Tiger opened the President's Report with a brief history on NHOPA and extended thanks to GRQ for providing NHOPA Executive Office duties pro bono.

Membership is on the increase with an 83% 2007 membership renewal rate. Currently there are 584 members (all categories) which is a 4.8% increase from November of 2006.

There has been a 29% increase in corporate and 38% increase in Health Professional memberships.

During 2007 NHOPA undertook a Pulmonary Rehabilitation Center Recruitment Project in which 700 rehab facilities were identified nationally. An informational letter about NHOPA was sent to each facility; health professionals and their patients were invited to become members. A 3.2% return was generated the first month of the mailing.

The User-to-User Directory is an ongoing project. Future additions to this directory will include corporate sponsor/member information. As has been in the past only User Members who consent to be included in the Directory will receive the directory; corporate sponsors will not receive directories.

Executive committee meeting minutes are now being sent to the full Board.

Major updates to the NHOPA website have been completed. Ongoing updates will be made on a regular basis as information is provided. A corporate sponsor webpage will be added to the site in the new year and will list participating corporate sponsors who wish to be included along with their logo and a link to their website.

The information previously published in the booklet *Airline Travel with Oxygen* has been updated and placed on the NHOPA website. In the new year a web page will be added with guidelines for other forms of travel.

The Understanding Oxygen Therapy booklet update is in final review and editing.

Events that have put NHOPA in the spotlight this year include a developing relationship with American Association of Respiratory Care (AARC). At the AARC's International Congress, held in December, Board Members Kent

Christopher, MD, and Stephanie Diehl, RRT and NHOPA President Jon Tiger will be part of the AARC program agenda as speakers. Jon will speak on the patient's perspective on long-term oxygen therapy with Dr. Christopher and Stephanie speaking on their respective clinical perspectives.

At the American Association of Homecare national meeting NHOPA was selected to receive a \$16,000 unrestricted grant. This grant helps to support publication of this newsletter and other NHOPA activities.

At the NAMDRC National meeting in March, Jon Tiger presented NAMDRC's Jacob Javits Award for Humanitarian Service to the Honorable Norman Y. Mineta for his efforts as Secretary of Transportation to get POCs approved for in-flight use.

NHOPA was represented by Jon Tiger at MedTrade in October, 2007 where many contacts were made with individuals interested in helping NHOPA membership grow.

Several governmental issues have been at the forefront for NHOPA in 2007. NHOPA initiated a grass roots e-mail effort to Congress members regarding the 2007 SCHIP and Medicare Package and its impact on oxygen users.

NHOPA continues to watch for impacts on patients and oxygen resulting from the implementation of competitive bidding.

A letter was submitted to the House of Representatives Ways and Means Health

National Home Oxygen Patients Association

8618 Westwood Center Drive Suite 210

Vienna, VA 22182-2222

1-888-646-7244

ExecOffice@homeoxygen.org

www.homeoxygen.org

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.

Executive Committee

Jon Tiger, President Wichita, KS
Robert Keith, Vice-President Baltimore, MD
Secretary/Treasurer – Executive Office

Newsletter Editor

Stephanie Diehl, RRT Littleton, CO
stefmistr@aol.com

Subcommittee addressing NHOPA's recommendations:

- Basing oxygen payment on beneficiary need
- Retesting (with reimbursement) of patient's oxygen need at 60-120 days after initial certification.
- Repealing the ownership provision

NHOPA visited Washington DC to lobby Senate members to address the ownership issue and exclusion of exemption for liquid oxygen.

NHOPA supported the Pulmonary and Cardiac Rehabilitation Act of 2007 (S329/HR552) designed to provide Medicare coverage Pulmonary Rehab.

The meeting was then opened to participating members for questions and comments. Suggestions from members that will be pursued include the cultivation of relationships with other patient organizations such as Alpha-1, EFFORTS, and COPD Alert.

NHOPA will also reassess the feasibility of online membership payment. Currently applications can be submitted online but payment must be mailed by check.

The meeting was adjourned at 12 noon ET.

Questions and Answers

Colleen Stripling wrote "Could you publish the latest information on Prednisone taken orally. I am on my last breath these days and am ready to try anything before I'm totally useless. My doctor seems to feel I've lived way too long already. I do want to see a female President before I die. I was taking 5 mg a day when I was feeling bad. After [my] last CT scan and other tests two years ago, [my pulmonologist] said there was nothing more he could do for me. My primary doctor is an internist. She prescribed the Medrol Dosepak generic equivalent. I have taken them several times. They help a bit. However, as soon as I go off of them in a few days I'm in very bad shape."

Colleen thanks for a great question regarding prednisone. Prednisone is a steroid that can be used to treat a variety of conditions. It can be given either as a short term medication, such as the Medrol Dose Pak, or in low doses over long periods of time if a person's condition warrants. Long term use of prednisone previously was the initial drug prescribed in the treatment of lung disease due to the lack of other medications

available. Advancements in medicine have brought new medications, such as inhaled steroids, onto the market and give physicians a wider choice in prescribing medications. Research of prednisone is ongoing and medicine continues to learn more about its use. One caution: people often mistake the steroid prednisone, used to treat lung disease, as the same type of steroid (anabolic) used and associated with body builders. Anabolic steroids have a different mode of action and outcome than prednisone.

Steroids for lung disease can be administered in 3 different ways: IV, orally by pill or liquid or orally by inhalation. Each however may have inherent side effects. According to the website Medline Plus (www.nlm.nih.gov/medlineplus) which is a service the National Library of Medicine and the National Institute of Health, some side effects of prednisone may include:

- headache
- dizziness
- difficulty falling asleep or staying asleep
- mood swings or changes in personality
- bulging eyes
- acne
- thin, fragile skin
- red or purple blotches/lines under skin
- slowed healing of cuts and bruises
- increased hair growth
- changes in how body fat is spread around
- extreme tiredness
- weak muscles
- irregular or absent menstrual periods
- decreased sexual desire
- heartburn
- increased sweating

Taking prednisone may decrease your ability to fight infection and may prevent you from developing or recognizing symptoms if you get an infection. Side effects with inhaled steroids may be minimized however you should consult your physician or pharmacist for a complete listing of side effects of steroids.

When taking steroids as a pill or liquid, it is best taken with food to decrease stomach irritation.

When steroids are taken as a metered dose inhaler (MDI), such as Flovent, or a dry powder decreases the likelihood of thrush which is an inhaler (DPI) such as Advair or Azmanex always take care to rinse your mouth after use.

This infection of the mouth is caused by the candida fungus, also known as yeast.

Just like other medications, prednisone should be taken according to your physician's instructions. Always make your physician aware if you are allergic to prednisone or if you are having surgery while taking prednisone. Consult your physician for further information on specific questions related to your health and the use of prednisone.

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.

Cramer Decker Medical has designed a new oxygen cylinder bag called the O2 Sidekick. This bag begins as a roller bag but may convert to a backpack or a shoulder bag. The product description states "This bag is constructed from washable, heavy-duty denier, has a large external mesh water bottle holder, embroidered carrying handles for easy pick up, a large external zippered pocket, and is lined with reflective silver piping for easy visibility at night. The bag can accommodate M2, M4, M6, M7, ML6, M9, MD, MJD, or even ME cylinders. An inside zippered pocket extends a panel to cover the taller ME size cylinder."

The bag is 23.5" long x 10.5" wide (base) x 8.5" deep and weighs 4.75 lbs. More details can be found at www.cramerdeckermedical.com or the company may be contacted at 877-222-0200.

Ellen Dobrin wrote in response to the retractable tubing reel question in the October newsletter. "I just received your latest newsletter. In answer to Kelly Jorgensen's question, Colvin Designs used to make a retractable tubing reel, similar to what is used for outdoor hoses stored on a reel. With this you just pulled the tubing out or to get it back you tug slightly, like the old fashioned window shades."

Ellen thanks for the feedback. We were unable to verify this particular manufacturer as their website is currently under construction however they are located in Lubbock, TX and they may be contacted at 888-870-5266.

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8618 Westwood Center Drive, Suite 210

Vienna, VA 22182-2222



*Happy Holidays
And
Happy New Year*



From the NHOOPA Executive Office and Board of Directors

I Didn't Know That.....

(Received via email – anonymous)

Q: Why are people in the public eye said to be "in the limelight"?

A: Invented in 1825, limelight was used in lighthouses and stage lighting by burning a cylinder of lime which produced a brilliant light. In the theatre, performers on stage "in the limelight" were seen by the audience to be the center of attention.

Q: Why do ships and aircraft in trouble use "mayday" as their call for help?

A: This comes from the French word m'aidez -meaning "help me" --- and is pronounced "mayday."

Q: Why is someone who is feeling great "on cloud nine"?

A: Types of clouds are numbered according to the altitudes they attain, with nine being the highest cloud. If someone is said to be on cloud nine, that person is floating well above worldly cares.

Q: Why are zero scores in tennis called "love"?

A: In France, where tennis first became popular, a big, round zero on scoreboard looked like an egg and was called "l'oeuf," which is French for "egg." When tennis was introduced in the US, Americans pronounced it "love."

Q: In golf, where did the term "Caddie" come from?

A: When Mary, later Queen of Scots, went to France as a young girl (for education and survival), Louis, King of France, learned that she loved the Scot game "golf." So he had the first golf course outside of Scotland built for her enjoyment. To make sure she was properly chaperoned (and guarded) while she played, Louis hired cadets from a military school to accompany her. Mary liked this a lot and when she returned to Scotland (not a very good idea in the long run), she took the practice with her. In French, the word "le cadet" means "the boy" or the youngest of the family and cadets were often the young sons of the aristocracy.

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