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*PERF, The Pulmonary Education and Research Foundation, is a small but vigorous non-profit foundation. We are dedicated to providing help, and general information for those with chronic respiratory disease through education, research, and information. This publication is one of the ways we accomplish these goals. The Second Wind is not intended to be used for, or relied upon, as specific advice in any given case. Prior to initiating or changing any course of treatment based on the information you find here, it is essential that you consult with your physician. We hope you find this newsletter of interest and of help.*

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**KEY WORDS:** ATS International meeting, Posters, COPD, US COPD Coalition, Upcoming events, Oxygen Conserving Devices, NLHEP,

Do you remember back in April we told you that if you had attended the CSPR annual meeting you would have been pleased by all the interest and excitement everyone had about pulmonary rehab? Well, if you had been able to wander around the **98<sup>th</sup> Annual International American Thoracic Society Conference** in Atlanta this May you would have been dumbfounded. ATS is an international professional organization dedicated to respiratory and critical care medicine. Despite these troubled times, with terror and strife plaguing our world, the best of mankind's nature prevailed here. Everyone present was united in the common cause: defeating pulmonary disease. The air pulsated

with comraderie, energy and excitement as the 14,000 attendees, from almost every country in the world, rushed from one meeting or seminar to another. So much was going on that it was literally impossible to attend everything of interest.

**Posters** are one of the highlights of each conference. What is a poster? Well, *these* posters are not like the big glossy pictures used to promote movies. They are a brief description in *words* of a research project that may have taken weeks, or even years, to complete. They may have been done by a young researcher working alone, or by a large group of the world's

leading scientists. Subjects range from the esoteric molecular biology research, to a study on hiccups in cats (welcome after that molecular bit!), effects of a new medication, and so on and on: *thousands* of posters are there, to be viewed and discussed with the researchers presenting them. One thing was obvious. The big push, the hot topic, the big interest this year was COPD. Poster or seminar, from all over the world, COPD seemed to be the big interest.

This is appropriate. COPD is the 4<sup>th</sup> leading cause of death in the world and in a few years will be 3<sup>rd</sup>. It is the only disease that is rapidly increasing instead of declining. The number of women afflicted is rapidly catching up with the number of men. Worldwide, smoking continues to increase so these numbers are expected to get worse rather than better. Denmark has the dubious distinction of now being the only country in the world that has more women than men smokers. Can you guess why? The queen of Denmark is a smoker and proudly appears in public with her cigarettes. The young women of Denmark are emulating their Queen, just as American girls in an earlier generation attempted to mimic the sophistication and “glamour” of smoking movie stars. How sad.

Enough research was presented to fill several newsletters but perhaps you would first like to know what is

happening politically, to make the public and our government take notice of this problem, and so take action. What are we doing to make these new advances available to all of you? How can we help insure that funds are available to pay for these new medications and treatments when they come on the market?

At ATS the **U.S. COPD Coalition and the ATS Public Advisory Roundtable (ATS-PAR)** held a **COPD Roundtable** meeting designed to meet this need. This COPD Roundtable meeting had one representative from most of the patient-centered and professional organizations concerned with respiratory illnesses and COPD. (Mary Burns represented PERF). Most importantly, also there, lending support and leadership were representatives of **ATS** (The American Thoracic Society), **GOLD** (Global Initiative for COPD), as well as **Dr. Claude L’Enfant, Director of NHLBI (National Heart, Lung and Blood Institute)**. **NHLBI is a division of the National Institutes of Health (NIH)**, the governmental body responsible for promoting medical research. **Suzanne Hurd, PhD the well known Director of the Lung Division of NHLBI and of GOLD** helped lead the meeting. The government is now backing us! These are very important people on the national scene and in a position of influence. The message was that *now*

is the time to join together and ***build a meaningful collaboration of all groups serving the COPD community. We need to form a nation-wide association advocating for emphysema and COPD patients.*** In the past, these various groups have each gone their own way, often duplicating efforts. We need to consolidate so that we don't splinter our effectiveness at accomplishing our goals. *There is strength in unity!*

Dr. L'Enfant spoke about the slow progress that had been made on this disease in the 40 years that he has been working on it. He stressed the need to work better, faster and use everything that we know. The Global Initiative for COPD (GOLD) is a big step towards this. In partnership with NHLBI it is designed to increase awareness, improve diagnosis and management and promote research. He reminded us again that there is strength in our numbers!

A roundtable discussion, lasting several hours, provided a lively exchange of ideas on where we should start first. The Coalition will try to raise awareness of COPD by

- Maintaining a website linked to Coalition members with information about their programs and activities.
- Promoting activities of Coalition partners.
- Making ***National COPD Awareness Month*** a yearly

event. President Bush has named this November as the first National COPD Awareness Month.

- Gaining the consensus of partners on key messages about COPD and communicating them to a national audience.
- Planning a National Conference on COPD. The first one will be in Washington, DC on November 13-15, 2003

Several committees were formed, all of which will have a patient representative. The top five advocacy issues identified by participants were:

- Reimbursement for pulmonary rehabilitation, oxygen and other medications.
- Access to insurance and care for COPDers.
- Funding for COPD research.
- COPD awareness.
- Providing information on newly introduced medications, equipment and health services for COPD patients.

The goal of more education extended to the members of Congress, as well as patients and the public. Congress decides how much funding should be allowed for rehab (and for research!). *Did you know that only 14% of the population knows what COPD is?* It is small wonder that Congress ignores our needs. How do we get the funding that much smaller

advocacy groups get for *their* members? **Here is how all of you can start to help right now.** We need to get the attention of Congress by writing to our individual representatives about our problems and needs. They DO pay attention to their home constituents! We also need to enlist the support of celebrities, or well-known individuals, to help our cause and to help the public know more about this condition. **While there are about 16 million people in the United States diagnosed with COPD it is estimated that there are *another 16 million* who have this condition but are unaware of it, or of the help that is available to them!** All of these people have family and friends. Surely, among all of our readers, there is someone who has a contact in the government, or with a well-known individual, that they are willing to approach. Or perhaps you yourself are willing to be a spokesperson. **Please call (310) 530-8390 if you have any ideas about how we can further this cause!** You can also reach the Coalition web site at [www.uscopd.com](http://www.uscopd.com) for more details on all of this information. **The time has come. We need to rise up and make our voices and our needs known. Please join us as we work with this Coalition to help those with respiratory disease!**

*Special thanks to Jo-Von Tucker of the Cape Cod COPD Support Group and the American Institute's Emphysema/COPD Composite Program for sharing her notes with Mary on this exciting meeting. You may better know Jo-Von as the Poster gal for the Helios oxygen system and as one of the authors of "Courage and Information".*

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### **WE GET MAIL**

*Brina Luther has made a donation to the PERF Alice Moore Memorial Fund.*

*Reta Long and Jeanne Rife made memorial donations for Lillian Fay.*

*Peggy & Warren Johnson made a contribution in memory of Dorothy Rollino.*

Special hello to long time reader **Tjaakje Heidema** who writes that we have a knack for boosting egos and making the quality of life so important. Thanks, Tjaakje. We try.

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### **UPCOMING EVENTS**

The UCLA School of Medicine and the Coalition for **Pulmonary Fibrosis** (CPF) will host a free educational seminar in Los Angeles at the UCLA School of Medicine on Saturday, June 8, 2002 from 9:00 am-12:30 pm. For more information call 888-222-8541 or visit their web site at [www.coalitionforpf.org](http://www.coalitionforpf.org).

The next **Southern California CSPR** meeting will be on Monday, June 17<sup>th</sup> in the Rehabilitation Clinical Trials Center at the Harbor-UCLA Research and Education Institute in Torrance, CA. Call **(310) 539-8390** for further information.

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### ***Demand Oxygen Conserving Devices for Compressed Gas Cylinders***

*By Craig Murga, RCP, Center Manager of the Torrance, CA Lincare*

We received an e-mail recently asking us to recommend the best oxygen-conserving device (OCD) available. Five years ago, with so few devices on the market, this would have been a much easier question to answer. Today, many manufacturers are producing quality devices and, of course, each one will lay claim to having the best product on the market. We should congratulate all the manufacturers for their efforts in the research and development of new products that allow oxygen dependent patients to enjoy a better quality of life.

Almost all the manufacturers that currently produce OCDs uses the **demand mode** rather than **time cycled pulse dose** method of delivery. The *demand mode* enhances the ability of the OCD to maintain proper oxygen saturation while also allowing greater ease in detecting a problem. **The most important consideration when**

**selecting an OCD is to be sure that the device will allow the user to maintain adequate O2 saturation, while also providing the longest duration of oxygen use per cylinder.**

No OCD should *ever* be placed on a patient without a doctor's order, or without testing the user on the device using oximetry to verify effectiveness. Any oxygen provider that carries these units should have a respiratory therapist or nurse on staff who will provide this service without any extra cost. *If an oxygen provider does not maintain a respiratory therapist or nurse on staff to provide this service, it's time to change oxygen companies.*

The test should be performed with oximetry while walking the patient for an extended period of time, during normal conditions of exertion, while carrying the system. If the user fails the test because of oxygen desaturation, the procedure should be repeated while on a continuous flow of oxygen. If a continuous flow provides adequate saturation, you may find that using a device with a lower ratio of saving may provide better results.

All manufacturers test their devices to determine the ratio of savings. In other words, if the manufacture has rated the device as having 2:1 savings, oxygen should last twice as long with the conserving device as it would with continuous flow oxygen while

maintaining the same oxygen saturation.

Some manufacturers have engineered their device to provide a larger pulse of oxygen at the beginning of inspiration, attempting to mimic the flow curve of diseased lungs. This may serve to meet the needs of a larger portion of the general population but *each individual's lungs are unique*. The savings ratio gives the user *a rule a thumb* when selecting a device, but this does not always translate into true savings. The best way to know how long any given cylinder will last is by having the user time their *individual* length of use with the equipment.

I am of the belief that when it come to OCDs, *simpler is better*. In other words, the fewer bells and whistles, the less that can go wrong with the device. Some users will gain added confidence with a device that provides a visual response. In most cases, however, adding components to the unit also increases the *weight* of the device. Some other suggestions to

consider when using conserving devices:

- Never use an OCD while sleeping.
- Never use extension tubing on an OCD.
- If the device uses a battery, have an extra battery ready to change if necessary.
- If the user has a cold, flu, upper airway obstruction, or exacerbated disease process, use a standard regulator until the problem has passed.
- If the user's respiratory rate dramatically increases, retest using oximetry.
- If someone feels the device is not operating properly, retest with oximetry.
- If the OCD does not have the continuous flow option, have a standard flow meter ready for emergencies.
- If the user's oxygen saturation is not supported by the OCD, try a device with a lower savings ratio.

**Demand Oxygen Conserving Device Comparison** gotten from the manufacturers

Manufacture	Model	Savings Ratio	Mode of Operation	LPM settings	Weight	Features
AirSep	ImPulse elite	6 : 1 and 3 : 1	Electronic	1 - 6	24 oz	Only ODC that has 2 setting for ratio of savings, a continuous flow switch,

						and standard cannula
Invacare	Venture Demand	6 : 1	Electronic	1 – 6	16 oz + 9 oz	Continuous Flow switch, standard cannula. The unit also needs a step down regulator (add 9 oz)
CHAD Therapeutics	411 A	5 : 1	Electronic	1 - 6	19 oz	Continuous flow switch @ 2 lpm, standard cannula
Precision Medical	Easy Pulse	4 : 1	Pneumatic	1 - 5	12.7 oz	Continuous flow switch @ 2 lpm , standard cannula
DeVilbiss	EX-2005	3 : 1	Electronic	½ - 6	26 oz	Continuous flow switch, standard cannula
Salter Labs	O2 Express	3 : 1	Pneumatic	½ - 6	16 oz	<b>No</b> continuous flow, dual cannula
Victor Medical	Demand II	3 : 1	Pneumatic		22 oz	Continuous flow switch, dual cannula
CHAD Therapeutics	OXY Pneu-matic	3 : 1	Pneumatic	1 - 6	14.8 oz	<b>PENDING FDA APPROVAL</b> Continuous flow switch @ 2 lpm , standard cannula

Western Medical	OPC-830	2 : 1	Pneumatic	½ - 5	22 oz	Continuous flow switch, dual cannula
Mallinckrodt	CR-50	2 : 1	Pneumatic	¼ - 6	17 oz	<b>No</b> continuous flow, dual cannula

The oxygen savings ratio is based on information supplied by each manufacturer with a 20 breath per minute cycle vs. the equivalent continuous liter flow setting.

*Many thanks to Craig Murga for this informative article. He will be writing a companion piece on other types of conserving devices for a forth coming newsletter.*

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### **NLHEP News** *from Dr. Tom Petty*

The **NLHEP** is gaining momentum as it enters its fifth year of operation. The partnership with NLHEP and the **AARC (American Association of Respiratory Care)** continues to grow. The AARC represents 130,000 respiratory care professionals who are in virtually every hospital in the USA. Thus, they are becoming the foot soldiers for the implementation of the NLHEP in pursuit of our goals of early identification and intervention of COPD and related disorders.

Recently, Mrs. Gretchen Lawrence, a senior respiratory therapist and a Master of the AARC has been hired to assist with program development. She is the liaison to the Dallas Office. Our two booklets, *Prevent Emphysema Now*, and *Save Your Breath America, Prevent Emphysema Now*, written for the primary care physician and patients respectively, are available from the AARC.

The NLHEP along with the Oklahoma State University and the Tulsa Regional Medical Center conducted a comprehensive program for primary care MDs and DOs in Tulsa on February 16. Speakers were Tom Petty of Denver, and Jim Seebess, DO, Chairman of the Department of Medicine at Oklahoma State. The "dynamic duo" covered the pathogenesis, epidemiology, course, and prognosis of COPD. Practical approaches to smoking cessation and treatment of symptomatic patients were discussed in detail. The use of home oxygen, pulmonary rehabilitation, and surgical treatment received emphasis. A practical discussion and demonstration of simple office spirometry completed the program.

*The entire program will soon be available on a CD, available from the department of medical education of the Tulsa center.* It is hoped that this model can be repeated throughout the USA in the months to come.

*Stay well until we next meet.....☺☺☺*