

## **OCTOBER-NOVEMBER**

2001

PERF, The Pulmonary Education and Research Foundation, is a small but vigorous non-profit foundation. We are dedicated to providing help for those with chronic respiratory disease through education, research, and information. We hope this newsletter is worthy of our efforts.

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ave you gotten you flu shot vet? We certainly hope so! While influenza vaccine is not 100% effective it is good insurance against getting the flu, or of getting a serious case of it. An annual flu shot is always important for those of you with respiratory problems, but this year more so than ever. necessary for us to go into the details respiratory anthrax? probably have heard more than you want to know about the symptoms and the victims. To be realistic, at this time, you have a greater chance of being struck by lightning than of respiratory getting anthrax.

Influenza is a far more serious risk for any of you, killing more than a thousand people each However, influenza is a naturally occurring event while anthrax is a tool of terrorists, and understandably causes more fear. Getting your flu vaccine may also help to prevent suspicious respiratory symptoms and panic leading to unnecessary visits to the ER or your doctor's office. So, whatever your reasons, don't delay, make arrangements to get you influenza vaccine TODAY!

Do you think that *you* have been inundated with information about bioterrorism from PBS, CNN, and

your local TV stations, not to mention the newspapers? Well, it might reassure you to know that health care professionals receive even *more* information, by e-mail and Internet from the CDC (Center for Disease Control), state medical associations and a number of other sources.

This detailed information is on identification, symptoms and treatment of potential infectious diseases, as well as plans on how to mobilize for emergencies. Does that mean that the medical profession in this country knows something that don't know, and expects vou epidemics? No. No more than you feel sure your home will burn down when you investigate fire insurance. It is just prudent to be prepared. When you know you have done all that you can, it takes away some of the anxiety you may be feeling.

Deciding what information is of value to you, our readers, is a challenge. We will review some of the basics, even though you may have read them elsewhere. The following information is a brief synopsis of material obtained from the Nov. 6 issue of the New England Journal of Medicine, as well as other sources, such as the CDC.

<u>Respiratory Anthrax</u> It had been more than 20 years since a case had been seen but, based on this, it is

thought it can be as many as 60 days after the spores are inhaled before symptoms occur, when caused by bioterrorism rather than natural The incubation period is usually 1 to 6 days. It starts with symptoms that mimic the flu, or an acute exacerbation of COPD. There is mild fever, fatigue, dry or nonproductive cough, along with some chest and abdominal pain. If you get these symptoms how can you tell what it is causing you to feel this way? You can't! You do the same thing you would do if there weren't any bioterrorism scare. your common sense and call your physician immediately. physician will know what tests to and what use. treatment appropriate. *None* of our readers ignore should anv of these symptoms at any time, even if we were not in the midst of a terrorist All respiratory patients threat. should practice early intervention to avoid a serious illness.

The second stage of respiratory anthrax starts 2 to 3 days later with an abrupt increase in fever, acute shortness of breath, sweating and cynosis, which is a blue tinge to the nail beds and lips. Remember, even respiratory anthrax can be cured if treatment is started in the first few days of symptoms. Again, it is important to get an early evaluation of any of your symptoms.

**Skin anthrax** The incubation period is usually one to seven days after contact, with 5 days being average. The skin lesions are painless but may tingle or itch. They usually appear on the hands or exposed surfaces of the skin. Initially it is described as a puritic papule. That means an itchy pimple. After the second day vesicles, or redness, appear around this area along with non-pitting edema. There is a low grade fever and fatigue. It looks like a bad spider bite, such as the one from a brown recluse spider. When the pimple ruptures it looks like an ulcer with a black scab in the middle. This scab falls off in one to two weeks with little scarring. It is easily treated with antibiotics and we are sure that no one with such symptoms would hesitate to seek medical attention! Treatment with antibiotics is usually 7 to 10 days for naturally occurring skin anthrax but 60 days for anything acquired as a result of bioterrorism.

## **Prevention**

Hand washing, hand washing and more washing of the hands is your number one defense against respiratory infections of *any* kind, as well as against skin anthrax.

**Antibiotics** should never be used without a physician's okay. Save them for when you really need them. Don't use them unnecessarily and

develop an immunity. Besides, you can get side effects.

There is a lot more information out there and we keep learning new things all the time. The summary above is not meant to provide all of the answers, but we did want to cover a few of the details that are especially pertinent for respiratory patients. Watch your TV and newspaper for additional details and please call your physician for any symptoms that last more than a day.

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Congratulations to Hoag Memorial Hospital Presbyterian in Newport Beach which celebrated the 25<sup>th</sup> anniversary of its pulmonary rehabilitation program this August. Wow! Medical Director and MC Dr. Paul Selecky did his usual masterful job with humorous commentaries on the changes we have seen in pulmonary rehab and the care of the pulmonary patient. Dr. Brian Tiep did double duty as a speaker, and playing requests on his violin during lunch. We thought we would stump him when we requested a popular Japanese song for two visiting Japanese physicians this phase Brian? No way! To the amazement of the Japanese guests, and the laughing applause of the crowd, he immediately fiddled the requested song. Later he spoke on changes seen in oxygen therapy these past 25 years. Mary Burns spoke about pulmonary

rehabilitation around the world, which is an easy task these days. Pulmonary Rehabilitation may have taken root and blossomed here in Southern California 20 odd years ago, but it is now vigorously spreading its roots around the world.

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Donations were made for the Rehabilitation Chair by Mary Barkman, RN, MS, and also by James Lynch in memory of Martha Cammack. Paul Seleck y, MD made a very generous donation, becoming a member of the Long Beach 500 Club. Welcome, Paul!

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The California Medal established more than 50 years The criteria states that it is ago. awarded to an individual, within or outside the framework of American Lung Association of California (ALAC), who has made the most meritorious contribution to the cause, prevention or treatment of lung disease. This individual may be a physician, scientist, or educator. In October of this year, for only the second time in the history of the medal, it was awarded to two individuals. Richard Casaburi. Ph.D., MD and Mary Burns, RN, Mary is only the second BS. woman, the second non-MD, as well as the first nurse to receive this prestigious award SO she was especially honored and overwhelmed by this great honor. Mary and Rich were invited to the ALAC annual

meeting held at Lake Tahoe in October. It was a marvelous event! In his acceptance speech, Rich thanked the Lung Association for supporting his research in the past Burns thanked Mary encouraging him to start his research in rehabilitation. In her short acceptance speech Mary thanked all her patients for inspiring her, as well as thanking the many wonderful friends who helped her so much along the way. No friend has been more helpful than Rich Casaburi, so she was humbly honored to share this prestigious award with such a great scientist. Mary also hopes that her recognition will help to inspire her peers, and show them that their achievements also may someday be appreciated and recognized.

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Donations to PERF were made by the PEP Pioneers in loving memory of Joyce William, Ruth Brand, Bob Fletcher, and George Richey. Reta Long, Bette & Bill Addington, Marge & Ralph Baxter and Mary Burns also made donations in memory of George Richey.

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Are you interested in **lung volume reduction surgery** along with a pulmonary rehabilitation program *at no cost to you* and with no hassle from your HMO? If so, **act** *now*, or forever hold your peace! **The National Emphysema Treatment Trial** (**NETT**), sponsored by Medicare, is in the home stretch.

Further participants will be enrolled only through this Spring. March or April will be the cut off dates for acceptance so, if you are at all interested, now is the time to act. Check with your physician about your eligibility, as well as the name and phone number of the nearest participating medical center. Your doctor doesn't know the criteria or which center is nearest you? Not to worry! Just give us a call at (310) 539-8390 and we will research the pertinent information for you. Even if you are randomized to the pulmonary rehabilitation arm of the study, you come out a winner. So, if you are interested in this surgical procedure for COPD, don't delay!

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In our last newsletter we gave you some of the precautions about flying since the tragedy of September 11th from the perspective of Craig Murga, Lincare Manager. Mary would like to add some personal advice based on her recent flight to the California Medal award ceremony at Lake Tahoe, CA, followed by another flight back to Connecticut. While all airlines and airports seem to be different, she does NOT encourage any one with any physical disabilities to fly at this She had enough excitement and mishaps for a one hour sitcom. While it is funny in the telling, it is not so funny if you are stuck in some of these situations, especially if not feeling too well.

Of special concern were the long lines, hours long. In one case, a woman who had been sitting on the sidelines got in front of her husband as he was approaching the gate. While she tried to tell people she was unable to stand that long herself, she got little sympathy from the annoyed and tired people in back of her. The Point? Immediately request a wheel chair, curbside. This is no time to test your endurance, or be macho!

Try to get a seat assignment weeks early and request an aisle seat for easy access to the bathrooms on a long flight. The window seat is good for leaning against and taking a nap. Planes are flying at 100% capacity so it is difficult to change seats once on board. If possible, make sure you are not sitting in a seat that does not recline as happened to Mary on both flights.

Make sure you have nothing metal in your baggage. Mary's carry-on suitcase at Tahoe triggered all the alarms and alerted the National Guard with their rifles. Why? Because of her California Medal plaque! After the suitcase passed the explosives scan, the plaque passed another careful examination showing it also to be free of explosives. It was then duly admired by the young National Guard, much to Mary's amusement. (They are much cuter

than some of those security personnel!)

Unfortunately many of these security personnel speak little English in some airports. Understanding their requests, or having them understand you, can be an exercise in futility. Mary returned to California with an antique copper tankard. Remembering the excitement caused by her California Medal Plaque, she deliberately took it out of her carryon, and pointed it out, hoping to avoid a problem. It was still treated like a potential bomb, requiring the personal examination of the English speaking supervisor. The fact that she had tucked a few plastic inside seemed hairclips to be especially suspicious. The hair clips through sent the x-ray equipment separately, and no, they did not ring any bells.

Wear as little metal as possible. Buckles on shoes will cause you to tip toe past security in your stocking offending with the feet preceding you on the belt through the scan. Belts on both men and women need to be removed in some airports, no matter how important they are to your dignity. Watch out for your jewelry, ladies. While only women are supposed to pat down women, Mary twice had non-English speaking male guards get a little too personal trying to paw the pendant she was wearing. Similar and worse

experiences with under wire bras were experienced by other travelers.

Other tips. Make sure the battery on your nebulizer works. The man sitting next to Mary had dead batteries and no place to plug in the nebulizer. What to do? Why, take extra puffs on your MDI, of course. It also helps to sit next to a pulmonary rehab nurse for a crash course on pursed lip breathing and other rehab techniques! This gentleman was not prepared for the increased altitude and probably should have been on oxygen.

Before taking a trip, make sure you check with a pulmonologist to see if you need supplemental oxygen on a long flight where the cabin is pressurized to about 8,000 feet. Will you die without it? No, but you sure will be a lot more comfortable on the flight, and when you land, if your oxygen saturations haven't been in the low eighties for five hours! Can you use those little yellow oxygen masks that pop out of the overhead if you get a little short of breath? No, you can *not*. They are activated only by depressurization of the plane, when they ALL come tumbling down. There are emergency oxygen tanks on board, but that is just what they are for: an emergency. If your doctor thinks you will need it, order your own oxygen supply, preferably a week or two in advance of your flight.

Be sure and drink plenty of **fluids** to compensate for the dry air, which runs from about 4 to 10% humidity. Extra long lines and waits at the airport make it a good idea to bring along a bottle of your own water. Avoid carbonated beverages which are gas forming, and also alcohol, which can give you an unwanted Rocky Mountain high. The steam from hot tea helps a little to prevent dry mucous membranes in your respiratory system as well as acting as a mild bronchodilator.

I'm sure it isn't necessary to tell you to carry on all of your **medications**. Bring extras along in case you dump half a bottle on a bathroom floor.

**Warning!** Some airports will question your **inhalers** so be prepared to take them out of your carryon to explain them.

Since it is difficult to walk around these crowded planes be sure to do ankle rotations and leg lifts to prevent blood from stagnating and later causing a **blood clot** or **pulmonary embolism**. This has gotten a lot of publicity lately as the Second Class Cabin syndrome *but* it can happen up in first class also, folks, so don't forget to shake that leg!

Make sure to get your **flu shots** at least 2 weeks before the trip. That closed cabin is a good place to

exchange bugs with several hundred other people.

Finally, don't hesitate to order a **wheelchair** to bring you to and from the plane. Even if you are really in good condition the *airports* aren't! Besides, it seemed as if wheelchairs enjoyed their own express lane and bypassed hours of hassle.

Does it end here? Not if you are going to a hotel. Besides booking a non-smoking room, make sure you are near an elevator. Some of those rooms seem half a mile away from the elevator. You might also ask what conventions are booked while you are there. Mary's hotel had a Great Dane Convention with 375 dogs booked into her hotel. (Yes, some people slept with their dogs in their beds.) These are handsome, well behaved dogs but have you ever gotten into an elevator with a Great Have you ever seen a Dane? neighbor walk their poodle with a pooper scooper and baggies? In the early morning hours here dozens of people and dogs were wandering around the grounds with shovels and garbage bags! But it was an interesting experience. Attention went to the dogs and everyone forgot about Anthrax. A great vacation.

May the start of your holidays be happy and healthy. Have a wonderful Thanksgiving! ©©©

