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Legislative Changes!

Also inside: Calling Dr. Bauer Sharing the Health The Switch to HFA Inhalers On the Road with Oxygen

The **Pulmonary** *'aper*

News Magazine Volume 19. No. 4 July/August 2008

On the cover: Minnie and Marilyn Sundt, who uses trans-tracheal oxygen, party at Disney World!

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As we cannot assume responsibility, please contact your physician before changing your treatment schedule.

"Now that I'm gone, I tell you: Don't smoke, whatever you do, don't smoke." - Yul Brynner

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The Pulmonary Paper is a membership publication. It is published six times a year for those with breathing problems and health professionals. The editor encourages readers to submit information about programs, equipment, tips, or services.

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Celeste's grandchildren, Macy and Tayte, will hopefully resist the peer pressure to start smoking!

I would like to congratulate all of you who have ever given up cigarette smoking. It takes a huge commitment. Success rates have vastly improved with the use of nicotine replacement therapy and new medication. But scary reports from the nation's capital say efforts to reduce teen smoking have stalled in the past five years. States have lost funding for anti-tobacco efforts and companies use new tactics to capture new smokers. Legislation is pending before the U.S. Congress giving the FDA the authority to regulate tobacco products (S. 625/HR 1108.) As you know, your opinion counts with your elected officials!

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Home Oxygen and Equipment Legislative Changes on HR.6331!

The fight is not over yet, but on July 9, 2008, HR.6331, The Medicare Improvements for Patients and Providers Act, passed with more than the needed votes in the Senate by a 69-to-30 vote. The same bill passed the House by an overwhelming 355-to-59 margin just before the July 4 holiday. Thank you to both Democrats and Republicans for this success. Even Senator Kennedy, recovering from brain surgery, came to vote!

There are many parts of this bill that will affect people with respiratory problems.

- This act repeals the provision that you would take ownership of your concentrator after three years of continuous use. Although originally slated to begin on January 1, 2009, there were no codes, procedures or reimbursement determinations in place that would allow a home care company to service your equipment or provide portable oxygen. When asked if it made sense that a person with breathing problems make their way to a home care dealer to obtain or refill their portables, many elected officials agreed it did not!
- Presently, each state determines if they will pay for pulmonary rehabilitation. HR.6331 puts an end to this practice and ensures a nationwide Medicare coverage of this benefit for people with chronic lung disease. As we know, pulmonary rehab has been shown to give those with COPD a better quality of life while reducing hospital days and exacerbations.
- The competitive bidding program that began on July 1, has been delayed for 18 months. Questions remain to be answered as to what happens to the companies who have won the bids and have contracts with Medicare to supply services.
- There will be improvements and an extension of payments to rural providers.
- There will be improved availability and coverage of mental health services. The bill will help people at or near the poverty level (\$867 per month for an individual) get assistance with medications and medical bills.
- Physicians' fees were about to be cut by 10 percent. The passage of this bill gives them a modest pay increase instead. If the cut had gone through, the possibility existed that Medicare beneficiaries would not be accepted by a physician.



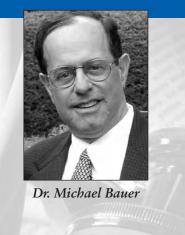
• New spending under HR.6331 will be offset largely by reductions in payments to Medicare Advantage plans. These plans offer optional drug coverage benefits and generally have higher co-pay amounts than a Medicare supplement plan. They may require that your primary care physician belong to their network.

Senators Obama and Clinton voted for the bill; Senator McCain did not vote. For a complete record of how your elected officials voted, go to www.vote smart.org/index.htm on the Internet. There were senators that are up for re-election this year who changed their vote from nay to yea after hearing from the people they represent – *you!* As we go to press, the bill has been sent to President Bush, who now has ten days to sign the legislation into law or veto it. White House representatives have said they expected the President to do so by the July 19 deadline because of the bill's changes to the Medicare Advantage plans. Since the bill passed both the House and Senate with more than enough votes, a veto will more than likely be overturned. Stay tuned!

Experts Shine Spotlight on Impact of COPD on Daily Life

United Kingdom experts in COPD are calling for healthcare professionals to place greater emphasis on the impact of the disease on patients' everyday lives. They want to focus on the potential positive impact that a COPD patient could experience, through effective management of their physical, emotional and practical needs.

Calling Dr. Bauer ...



My doctor recently told me that my carbon dioxide level was high. What does this mean and is it important? AS, Tully, NY

Most of us know that the job of the lung is to extract oxygen from the air and then deliver it to our red blood vessels. Oxygen is a vital ingredient for many of the chemical reactions that occur in our body all the time. When the fuels in our body utilize oxygen, a common byproduct is the production, or build up, of carbon dioxide in the blood. Too much carbon dioxide builds up the acid levels in our body and that is not good. Every time we exhale, our lungs help rid the body of excess levels of carbon dioxide. Our lungs are working during inhalation and also during exhalation!

When carbon dioxide levels rise, one of the ways our body compensates is to have us breathe more deeply and more rapidly. You can imagine that could be quite a stress for someone with severe COPD. Fortunately, it's usually only in the advanced stages of lung disease that high carbon dioxide levels are a problem.

It's relatively easy to treat low oxygen levels by administering supplemental oxygen with nasal prongs. It's a tougher problem to get rid of excess carbon dioxide. Optimizing lung function with a proper program of inhalers and medications is crucial. Medications that act as sedatives are to be avoided since they may decrease respiratory drive. Big meals all at once can build up carbon dioxide. Some patients may benefit from BiPAP-BiLevel Positive Airway Pressure-during sleep to increase breathing volumes which can be quite helpful.

In truth, our lungs and other body organs are remarkably efficient in fine tuning our carbon dioxide levels. Pulse oximeters can measure oxygen levels with a small clip on the finger. There is no similar device as simple to measure carbon dioxide levels. Thank goodness there is only the rare need for you or your doctor to measure carbon dioxide from day to day.

Question for Dr. Bauer? You may write to him at The Pulmonary Paper, PO Box 877, Ormond Beach, FL 32175 or by email at cbelyea@pulmonarypaper.org.

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Fibrosis File

The Coalition for Pulmonary Fibrosis (CPF) and the National Jewish Medical and Research Center have launched the first genetic counseling program for patients and families affected by familial pulmonary fibrosis. The telephonic counseling program will be operated by the National Jewish Medical and Research Center and funded by the CPF.

Pulmonary fibrosis is a disease characterized by progressive scarring of the lungs. Most cases are of unknown cause and are called Idiopathic Pulmonary Fibrosis or IPF. IPF affects an estimated 128,000 patients in the United States with about 48,000 new cases diagnosed each year. There is no approved treatment for IPF. An estimated 10 percent to 15percent of IPF patients have a form of the disease that runs in families. Recent research has identified two genetic mutations that are associated with familial pulmonary fibrosis, and tests for those mutations have recently become available to the public.

The genetic counseling program will provide a qualified genetic counselor, who has expertise in familial pulmonary fibrosis, to discuss by phone various issues surrounding familial pulmonary fibrosis. These can include preparation for and interpretation of genetic tests, and various life decisions, such as having children and planning for the future. Experts recommend talking to a counselor prior to having any genetic tests, so that people are prepared to learn the results.

"With a disease that has no FDA-approved treatment and no cure, it is incredibly difficult for people to deal with the diagnosis. When entire families are threatened by the disease, it is an even more devastating experience," said Mishka Michon, Chief Executive Officer for the CPF. "This counseling program will help patients and families to better understand what is known about familial pulmonary fibrosis and to make informed decisions for themselves and their family members with regards to their overall care, including genetic testing. We are pleased to support this important service."

For further information on the Familial Pulmonary Fibrosis Genetic Counseling Program or to speak with a genetic counselor, call 1-800-423-8891, ext. 1022.

Be sure to visit the new website of the Coalition for Pulmonary Fibrosis at www.coalitionforpf.org or call 1-888-222-8541. You will find lots of research news and information about support groups and upcoming events!

China Study:

Expectorant Carbocisteine Highly Cost-effective

The medical journal *Lancet* contains a study from China that shows the expectorant, Carbocisteine, is a highly cost-effective medicine that prevents exacerbation of COPD. The drug is not available in the United States.

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Ask Mark ...



Bette Hansen of Sun City West, AZ, writes, "I am fighting fear about losing liquid oxygen and, therefore, the use of my Helios. I am a terribly fortunate person who is able to play tennis, golf, bike and go to the gym. My doctors have told me the key to my life is to remain active and thus far, the results of exercise has kept me at a strong point. Now, I'm being asked to give up my Helios (which I wear around my waist). There is no current piece of equipment which I could use in the same way!"

Mark tells us, In this current climate, no one can "force" their oxygen company to do anything. A prescription for liquid oxygen (LOX) does not force a supplier to offer the service. Companies will continue to limit who will be offered LOX systems unless current Medicare legislation is changed. Under competitive bidding, LOX is a moneyloser even for the national companies.

With the current difficulties your oxygen company is facing in matters of reimbursement, the choice of LOX will become rare until the reimbursement turmoil is fixed. Some of our members who recently visited Las Vegas were told the city no longer has liquid oxygen at all!

Each type of oxygen system has its pros and cons. No system is inherently "the best" when compared to another. (You will find a lot of information about the different types of oxygen available from a user's perspective at www.portable oxygen.org).

I do not recommend one system over another since I feel strongly that it is up to the user to choose which system works best for him or her. For some, that may be portable tanks and concentrator combination. For others, it is the liquid system with self-refillable portables. A home concentrator with LOX provides the best of both worlds. There are concentrators that will fill gas or liquid oxygen portables and then there are the portable oxygen concentrators. I don't like it when health professionals insist their patients use only the system they like and recommend, regardless if it is appropriate to the needs and capabilities of the patient. Since you must deal with the idiosyncrasies of the system, I think the oxygen user should make the choice.

Gary M. from EFFORTS asks Mark to explain oxygen saturation readings and how a heart medicine, like Lopresser, affects COPD.

Mark says, Three components go into calculating the oxygen saturation percentage when you have your arterial blood gas drawn. Your pH, Carbon Dioxide (PaCO₂) and Oxygen (PaO₂) partial pressures are compared and factored together to arrive at a calculated saturation of the hemoglobin. Hemoglobin in the red blood cells is responsible for transporting and delivering over 99 percent of the body's oxygen supply. Pulse oximeters look only at the saturation without distinguishing what particular relationship between pH, PaO₂ and PaCO₂ is generating the measurement.

Lopressor is a beta blocker. Years ago, selective beta antagonist medications we used for bronchodilation caused problems. Today, all beta blockers continue to warn about the potential for beta agonists, such as Albuterol, to counteract beta blockers, such as Lopressor. The combination may either make the respiratory medication less effective in improving air movement, or interfere with the beta blocker's ability to control heart arrhythmias. Such problems are extremely rare with today's medications.

Mark Mangus RRT, BSRC, is a member of the Medical Board of EFFORTS (the online support group, Emphysema Foundation For Our Right To Survive, www.emphysema.net). He generously donates his time to answer members' auestions.

Of Interest

U.S. News and World Report recently listed the best hospitals in the country. The ten top centers for respiratory disorders were: National Jewish Health, Denver, CO; Mayo Clinic, Rochester, MN; John Hopkins Hospital, Baltimore, MD; Massachusetts General Hospital, Boston, MA; Cleveland Clinic, Cleveland, OH; University of California, San Diego Medical Center; Hospital of the University of Pennsylvania, Philadelphia; University of California, San Francisco Medical Center; Duke University Medical Center, Durham, NC; and New York Presbyterian University Hospital of Columbia and Cornell, New York, NY.

Feelings

It always helps to vent! If you or your caregiver would like to write about how you really feel about any aspect of chronic lung disease, we will credit you with a year's membership. Please send to: The Pulmonary Paper, PO Box 877, Ormond Beach, FL 32175.

I try to smile and hide my tears – It's getting harder. Breathing with oxygen all these years – It's getting harder. And at night comes all the fear – It's getting harder. Going up and down the stairs – It's getting harder. At times I feel that nobody cares – It's getting harder. And the next day, the sun comes up – And I try harder. CL, 22 years with COPD

C-O-P-D Defined in Rhyme

by Burton Bacher, Peoria, AZ (with apologies to Ogden Nash) Woe is me, woe is me. They say I've got C-O-P-D What does it mean? What does it mean? It can't be felt; it can't be seen

Just talking about this nasty disease Sure makes a person feel ill at ease

And because it's so hard to simply tell it We'll solve the problem – we'll simply spell it

- **C** stands for Chronic Which means that it can't be cured by a tonic
- **O** *is for Obstructive Which means your alveoli ain't so conductive*

P stands for Pulmonary Which is the doctor's fancy way of saying it's all in your lung (Don't know how you got yours, but I got mine because I started smoking so young)

D could stand for Disorder but doesn't – it stands for Disease (As far as I'm concerned, though, you can say it any way you darn please!)

And there is no way, there is no way, To make this thing go away

But there **is** a way we can control it We just have to make up our minds Yes, there is a way and I firmly extol it We've got to get into rehab and off our behinds

So I just keep repeating this mantra of hope Cause it cheers and uplifts me and helps me to cope

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Sharing the Health

Oxygen user Mary Jane Gormley of Bloomington, IN, can still play her harmonica while visiting the Continental Divide in New Mexico, elevation over 7,000 feet!



Our friend, Lori Palermo, would like to warn our members of a different kind of computer virus. A norovirus that causes stomach flu can be spread via computer mice and keyboards in schools, offices and at home. To help prevent illness, be sure to disinfect keyboards and mice regularly with a diluted bleach solution and wash your hands often. Q-tips and cotton balls are a very simple way to clean your keyboard and mouse.

For those of you who are planning events to celebrate COPD Awareness Month in November, Lori has her Gold Ribbon Awareness Lapel Pins available. Each pin may be purchased for \$3, which includes shipping, by writing to Lori at RR1, Box 1220, Gouldsboro, PA 18424.

I use a plastic coil with a clip on the end to attach a tank key to my portable bag. I have been on oxygen for just two months and find this very convenient when I have to change tanks. It does the job and is always there!

Shirley Ernst, Oconto, WI

My tip is for people like me who bruise easily (I attribute this to medication). I am embarrassed to wear short sleeves or show hands that have purple splotches on them. There is a product called Dermablend which helps to hide scarring and bruises. A corrective cream *Receive a Free One Year Membership* Contribute a picture or tip on how you COPE with COPD! Send to The Pulmonary Paper, PO Box 877, Ormond Beach, FL 32175. Include your name and address.

is applied and then a setting powder. It is available in most department stores. A sales associate can help choose the best colors for you. I feel more confident about how I look now when I go out with friends.

Fran Zimet, El Paso, TX

I found these tips on the Internet to help people with COPD make it through the hot summer. Just like in cold weather, I have to talk myself into braving the elements and going outside.

- Drink plenty of fluids
- Avoid rigorous exercise or excess activity
- Wear appropriate clothing and sunscreen. Lightweight summer clothes, such as light-colored, loose fitting garments, reflect the heat and allow you to perspire.
- Plan your activities carefully. If you have to go outside, do so in the early morning hours or after the sun goes down. When driving, park in shady areas, choose places to go that are air-conditioned and place sun visors in your parked car.
- Keep your cool indoors. If it is possible, stay indoors in an air-conditioned building. If you don't have airconditioning, plan your day to involve going to places that do, for example the library, a shopping mall or a friend or family member's home that is air-conditioned. Take a cool shower or bath to lower your body temperature. Avoid activities that involve utilizing extra energy.
- Use the buddy system. Make sure to have friends or family members call or stop by at least once a day to make sure you are OK.

Elaine Johnson, Knoxville, TN

Steve G. of Minnesota wanted to know how others overcome psychological blocks to do an activity. We found good advice in "COPD for Dummies" by Dr. Kevin Felner. Instead of focusing on why you should be active when you just don't have the energy, imagine your life as you would like it to be. Then take small steps toward your goals.

Remember the past - marathons may now be out of

the question but would you like to go to a park and watch one?

Think about how you feel emotionally Do you resent watching your wife carry in the bags of groceries? Once you understand your feelings, it gives you an element of control which is a big motivator.

Consider what you don't want. You don't want your symptoms to get worse? You don't want a trip to the emergency room? Then you better work at it!

Write down the things that motivate you and place the list where you can see it – on the bathroom mirror or refrigerator. Monitor your progress and accomplishments in a daily log book.

You can do this!

I have been on oxygen for ten years. I am now on 4LPM at rest but walk the treadmill every morning for 30 minutes. I feel like I have to stop after every five minutes, but I keep on until the end. I have a wonderful

Making the Switch to HFA Inhalers

King Pharmaceuticals has discontinued their Tilade inhaler (nedocromil sodium) used for asthma. Boehringer Ingelheim's Alupent (metaproterenol sulfate USP) metered dose inhaler will also no longer be available once current supplies are depleted. These inhalers contain chlorofluorocarbons (CFCs) as a propellant or spray, which are thought to harm the ozone layer. The earth's ozone layer protects all life from the sun's harmful radiation. In January 1989, the Montreal Protocol on Substances That Deplete the Ozone Layer set a deadline for elimination of CFC use that will take effect January 1, 2009.

Hydrofluoroalkane (HFA) propellants have similar properties of CFC propellants but are safer for the environment. Your medications now must be reordered as the FDA has determined that changing the propellant makes the inhaler a brand new medication. You will notice some differences.

The dose of the drug you get with a HFA inhaler is more consistent than that from a CFC inhaler, even when the inhaler is almost empty or the weather outside is very hot or cold. The spray from a HFA inhaler is warmer, the volume is less and it will feel softer, as it has a lower impact than a CFC inhaler.

It is very important that you use proper technique when you are using an inhaler. A valved holding chamber, such as the AeroChamber[®], should be used. Remember to hold your breath for ten seconds after a wife who does everything she can to help me cope with COPD. She has never once complained about all she has to do. In return, I help with keeping our apartment clean and making breakfast or supper two or three times a week. I also encourage her to go out with relatives and friends whenever she can, so she has a break. I think she is the greatest! **Don Paulsen, Council Bluffs, IA**

The cover of our last issue showed a prototype of an oxygen carrier that could be used while swimming. This was very exciting news for oxygen user, Marie Mortell of Wilton, CT, who would very much like to get back into the water. In 1948, Marie earned a gold medal as a member of the 4 x 100 meter freestyle relay swimming team in the summer Olympic games in London. Marie had seven children, including five girls who earned university swimming scholarships.

Any tips or suggestions on how to swim with a portable gas cylinder would be greatly appreciated!

slow, maximal inspiration to allow the medication to deposit in your lungs.

There are three albuterol HFA inhalers that the FDA has approved as safe and effective: ProAir® HFA, Proventil® HFA and Ventolin® HFA. Xopenex® HFA (levalbuterol tartrate) is also available.

Visit www.ProAirHFA.com to receive \$20 off each of your next five prescriptions of the drug. The Ventolin® HFA inhaler has a built-in counter so you know how many doses you have taken. Visit www.proventilhfa.com for instructions to receive a transition kit including a free inhaler and \$15 off your next two prescriptions.

When you use an inhaler for the first time, or if you have not used one in a while, the inhaler may not deliver the correct amount of medicine with the first spray. HFA inhalers have to be cleaned and primed to give the right dose of medicine. Each HFA inhaler has different instructions. The patient information that comes with each inhaler tells you how to clean and how many times to prime the device. To prime the inhaler, take the cap off and shake the canister to equalize the ingredients; hold the inhaler at arm's length and press the inhaler.

Please be sure to speak to your physician about your inhalers so you can receive and fill new prescriptions for HFA inhalers. The FDA reports almost half the people who use inhalers have not yet made the switch from CFC to HFA inhalers.

Traveling Tales

Seven Weeks on the Road with Oxygen

There have been many articles written about traveling with oxygen. I've read most of them because in the thirteen years I've needed supplemental oxygen, I've done quite a bit of traveling. This spring, my husband Andy and I took a long trip and we learned a few things. Needing supplemental oxygen is no reason not to travel around the country for extended periods of time if that's your idea of fun. We certainly had fun!

First comes the planning. This is important even for short trips, but extra important for long trips. We live in Denver, and wanted to visit family and friends in New Mexico, Texas and Florida and also see the tourist attractions in between!

My insurance dictates that I use Apria for my oxygen and supplies. I plotted our route with the Apria directory along with the maps, making sure we'd travel through cities with Apria branches. I use liquid oxygen, and we travel with two continuous flow portables and a large tank from which I fill the portables. About two weeks before we left, I called Apria to notify the branches I thought we'd need to visit. I also asked the customer service rep to check that each of these branches had liquid oxygen. She said that Harlingen, TX, only had oxygen on trucks, so I would need to call the



Inside a shark's mouth, on the beach at Corpus Christie, TX. It's the doorway to a souvenir shop.



On the Carrousel in the Magic Kingdom at Disney World

day before to be sure a truck was there. We always call the day before and double check that we have the correct address. I also always take a copy of my prescription with me.

I had an itinerary showing where we would be each day, when we'd need oxygen, when we'd need to mail checks to pay bills, and when we'd need to mail birthday cards! You can't put the world on hold just because you're not at home.

My packing list included oxygen supplies that are needed for any trip, short or long: extra tubing, cannulas, swivel attachments, Christmas trees, and all the supplies for my trans-tracheal oxygen. I bring an oximeter and a flow meter to check the tanks.

We had so much fun. Taking this much time for a trip allowed us to spend three or four days at each home we visited. We spent one or two days playing tourist between visits. We saw sights that weren't in the tourist information. We were in Mobile, AL, shortly after Mardi Gras, and while we were doing a walking tour of one of the many historical districts, we saw a tree absolutely covered with Mardi Gras beads. We spent five days in Disney World. I rented a wheelchair, so I wouldn't get too tired. It made it easy to carry both tanks and we could be in a theme park all day.

There will always be communication problems. You just have to expect it. Learn from it and then laugh about it after the fact. I learned that we will always plan on going to the branch for refills. If you really want to see the country, and have the time for it, long road trips are the way to go. Don't let your oxygen needs stop you!

Marilyn Sundt, Aurora, CO



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Radiofrequency Ablation Offers Some Hope

WebMd reports, "Radiofrequency ablation ("RFA") is a tumor-zapping device that increases survival in patients with small, inoperable lung cancers, according to an international clinical trial. RFA was used to zap 183 lung tumors in 106 patients rejected for surgery and considered unfit for radiation or chemotherapy. Despite the patients' frail conditions, RFA got rid of the tumors in all but one patient. Overall survival was 70% at one year and 48% at two years for patients with primary lung cancer, and 89% to 92% at one year and 64% to 66% at two years for patients with other cancers that had spread to the lung. None of the patients suffered worse lung function after undergoing RFA. RFA can only be used in relatively small tumors. Study patients had stage I or stage II lung cancer. The RFA device looks like a long needle with a handle on the end. Guided by CT scanning, a doctor inserts the needle into the lung, tiny tines are then deployed into the tumor. When the RFA is activated, intense heat in and around the tumor burns it away. The FDA approved RFA for use now in metastatic liver tumors and for general use in soft tissues, but it is not specifically approved for treating lung tumors."

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Respiratory News

News from Montreal is a "big step forward" in the potential treatment of incurable disease was made by genetically modifying the patient's own stem cells. An experimental treatment on two Quebec volunteers with pulmonary hypertension had an almost immediate drop in pressure in the lungs by 10 percent to 15 percent. Dr David Langleben of Jewish General Hospital said, "This is still at the very, very early stage, but we have nothing else to offer patients. To see something work so quickly and effectively is incredibly encouraging." The treatment appeared to halt the progression of the disease.

The medical journal *Chest*, reports Cornell University researchers have found a subset of genes might indicate a smoker's risk for COPD. "Despite the overwhelming evidence of cigarette smoking as the major risk factor for the development of COPD, the majority of long-term smokers remain healthy, strongly suggesting that genetic factors modify disease susceptibility," the authors note.

When you receive your yearly flu vaccine, the serum has been formulated against specific strains of flu that specialists feel will be the most prevalent. University of Pennsylvania researchers are working on developing a vaccine that will protect against strains of a potential worldwide avian flu pandemic. This vaccine is delivered via DNA where it becomes part of the cell by electroporation, a small, harmless electric charge. When exposed to the avian flu, your body will have the formula to fight it. Another study showed despite being at increased risk for influenza-related complications, almost two-thirds of people in the U.S. with asthma do not get their flu vaccine each year.

Having lower serum magnesium levels can predict if you will have an exacerbation (worsening of your symptoms as with an infection) of your COPD. Researchers followed 100 patients and found that 23% of them had at least three re-admissions per year. Their magnesium levels were the sole predictor of frequent re-admissions.