

The COPD Foundation

A message from the President

I love New York

The effort to battle COPD in the city

Hear it from the experts

Tips, research, and misperceptions

MEDIA PLANET

November 2010

PULMONARY HEALTH



3
TIPS

UNDERSTANDING COPD

DRIVE4COPD inspires us to put the breaks on America's 4th leading cause of death

PHOTO: DRIVE4COPD

Oxygen Anytime, Anywhere

Mark Junge uses Invacare® portable oxygen concentrators on his cross-country bike tours.



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CHALLENGES

It's time that we all stand up and scream, "I'm mad as hell and I'm not going to take it anymore!" It's time to join the Foundation and **declare war on this epidemic.**

Declaration of war on COPD

A dear friend of mine, Grace Anne Dorney Koppel, gave a keynote address at the American Thoracic Society's International Conference titled, "I'm Mad as Hell and I'm Not Going to Take it Anymore." As the spokesperson for the National Heart, Lung and Blood Institute's "Learn More Breathe Better" campaign, Grace Anne articulated her frustration—and exemplified ours—about the lack of government support for research, awareness and prevention, and the unacceptably high number of individuals misdiagnosed or undiagnosed with Chronic Obstructive Pulmonary Disease (COPD).

COPD is the fourth leading cause of death in the U.S., affecting over 24 million individuals and every four minutes an American dies from it. In 2010, American taxpayers paid approximately \$50 billion in health care costs for COPD—much of which could have been avoided with prevention and maintenance meth-

ods. Only 12 million of the Americans with COPD have been diagnosed (which means another 12 million don't know they have it) and it's a major cause of disability. Worldwide, it's estimated that 210 million have COPD.

These statistics are heartbreaking. Everyone in America knows someone with COPD and it's unacceptable that COPD will be the third leading cause of death by 2020. It's unacceptable that COPD is the only chronic disease that's on the rise and that millions of Americans don't have access to the therapies that could improve the quality of their lives.

It's time to declare war on COPD!

What does it take to get everyone's attention on COPD? Look at what's been accomplished with the war on cancer, HIV/AIDS and heart disease.

Today is World COPD Day—a specific time during November COPD Awareness Month where thousands of individuals, like you and me, are mobilizing to become

"Today is World COPD Day—a specific time during November COPD Awareness Month where thousands of individuals, like you and me, are mobilizing to become advocates, volunteer for research and spreading awareness."



John Walsh
Founder and President of the COPD Foundation

advocates, volunteer for research and spreading awareness. They're telling their loved ones to get tested for COPD if they have symptoms or have a history of COPD in their family.

This special insert will highlight some of the innovative research being conducted, advances in clinical care for patients and progress made with awareness such as the DRIVE4COPD and the Learn More Breathe Better campaigns. But this is simply not enough. As we say at the COPD Foundation: COPD is almost always preventable, almost always treatable and someday, curable.

It's time that we all stand up and scream, "I'm mad as hell and I'm not going to take it anymore!" It's time to join the Foundation and declare war on this epidemic. Let each of us join the War on COPD today and take this as a call-to-action to get involved and make our loved ones aware of the importance of getting tested. To join the movement, visit our website (www.copdfoundation.org) or call 1-866-316-COPD (2673).



WE RECOMMEND



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DRIVE4COPD

"People need to do a quick read of their health. I got involved with Drive4COPD because I want to make that happen."

Biking to tell the world

Mark Junge shares his story of being an oxygen-dependent cyclist. **p. 8**

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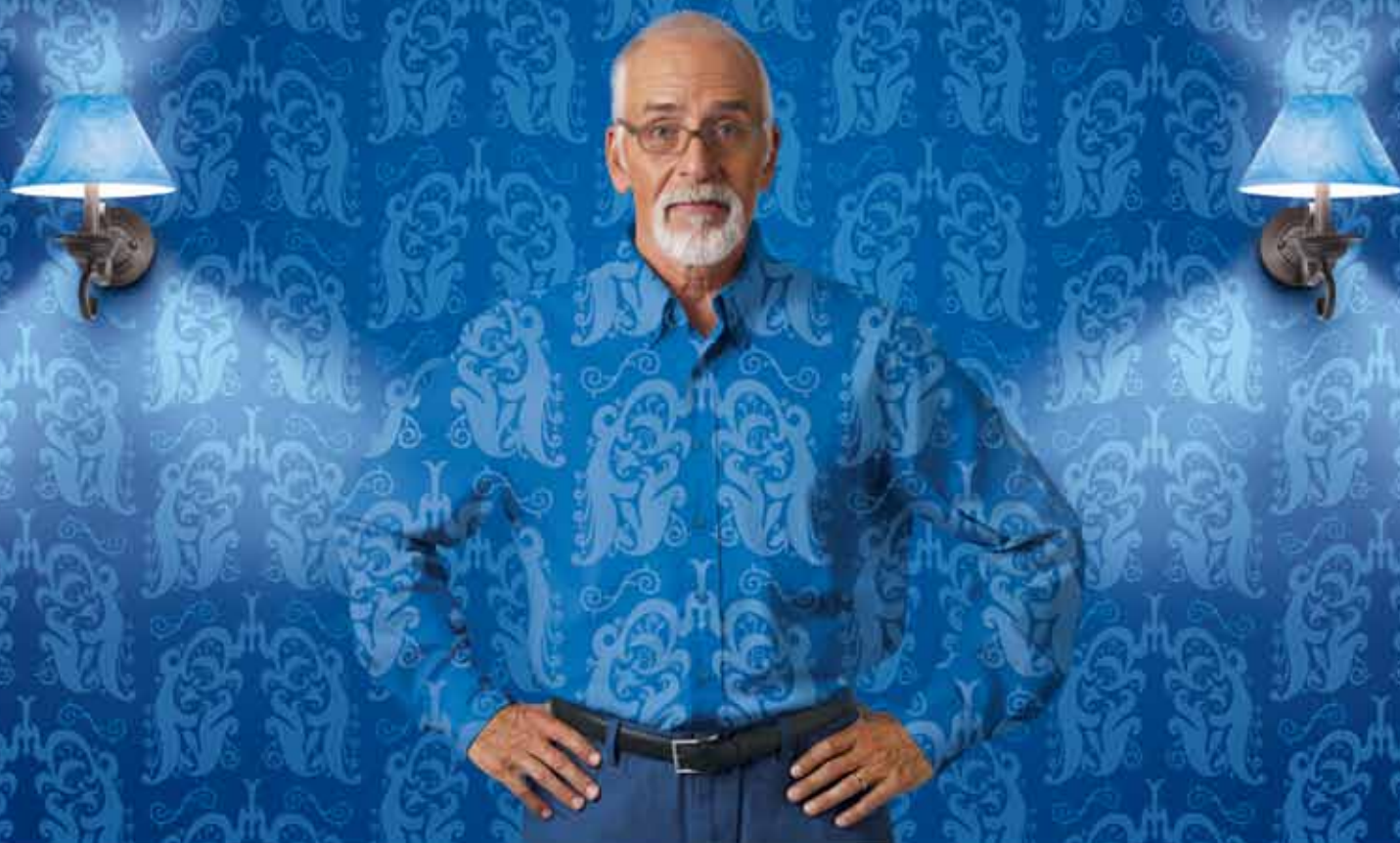
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A hidden cause of COPD may be right in front of you



ALPHA₁-ANTITRYPSIN DEFICIENCY (AATD) OFTEN GOES UNRECOGNIZED

AATD is the most widespread, potentially fatal genetic disease in Caucasians¹— and responsible for up to 3% of COPD cases in America.² Yet it is estimated that over 95% of Alpha-1 patients have not been identified² and are not getting treatment.

AATD TESTING—THE ONLY WAY TO KNOW FOR SURE

The American Thoracic Society (ATS) Guideline recommends testing³:

- All adults with symptomatic emphysema regardless of smoking history
- All adults with symptomatic COPD regardless of smoking history
- All adults with symptomatic asthma whose airflow obstruction is incompletely reversible after bronchodilator therapy
- Asymptomatic patients with persistent obstruction on pulmonary function tests with identifiable risk factors (eg, smoking, occupational exposure)
- Siblings of individuals with AATD

AATD CAN BE DIAGNOSED WITH A SIMPLE FINGER STICK BLOOD TEST

- Healthcare Providers: You can make a difference by testing more of your COPD patients

References: 1. Campbell EJ, Campbell MA, Boukedes SS, Owen CA. Quantum proteolysis by neutrophils: implications for pulmonary emphysema in α_1 -antitrypsin deficiency. *Chest*. 2000;117:303S. 2. Campos MA, Wanner A, Zhang G, Sandhaus RA. Trends in the diagnosis of symptomatic patients with α_1 -antitrypsin deficiency between 1968 and 2003. *Chest*. 2005;128:1179-1186. 3. American Thoracic Society/European Respiratory Society Statement: Standards for the diagnosis and management of individuals with alpha-1 antitrypsin deficiency. *Am J Respir Crit Care Med*. 2003;168:818-900.

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BIOTHERAPEUTICS

NEWS

TIP

1

QUIT SMOKING

Chronic Obstructive Pulmonary Disease (COPD) is a progressive lung disease in individuals with damaged airways. COPD results from cigarette smoking or exposure to an environmental insult.

The COPD Epidemic: Stealing a New Yorker's last breath

Six thousand New Yorkers will die this year from COPD alone. In New York, COPD is a major killer in the city and state. "The COPD epidemic is just beginning," said Byron Thomashow, M.D., Chairman of the COPD Foundation.

COPD affects 20-30 million people but only 13 million are diagnosed. COPD is the 4th leading killer in the United States and the numbers are growing. Estimates project that COPD will be the 3rd leading killer world-

wide by 2020.

People at risk for COPD include tobacco smokers, people exposed to environmental pollutants and mass-bio fuels. Approximately half of the world's population is exposed to bio mass fuels on a daily basis. Since the year 2000, more women were diagnosed, hospitalized and died from COPD compared to men. Recent studies indicate that women may be more susceptible to the effects of COPD.

Patients with COPD often suffer from a host of other serious medical conditions such as lung cancer, heart disease, osteopo-

rosis and depression. Unfortunately, patients with COPD are often undiagnosed and untreated for their condition. "There are FDA approved medications that improve quality of life and decrease exacerbations. These medications are available but they are underused", said Thomashow, M.D.

Typically, patients are prescribed short-acting as needed medications instead of long-term maintenance medication. "The quality of life is something that we can impact in all of these people", added Thomashow.

Asthma, acute and chronic bronchitis and emphysema are categorized under COPD but the symptoms and treatment of each differ.

Asthma

→ Asthma is a lung airway obstruction. Twenty percent of patients with COPD have

asthma as well. With proper diagnosis and prescription medication, asthma is completely reversible. Symptoms of asthma and COPD are similar and distinguishing between the two diseases is difficult.

Emphysema

→ Emphysema is a subset of COPD that occurs when the air sacs have been completely destroyed. The damaged air sacs inhibit the flow of oxygen throughout the body.

Bronchitis

→ Bronchitis is characterized by persistent coughing that causes mucous, chest pain and wheezing. Acute bronchitis lasts up to 10 days and is spread from bacteria in the air. Chronic bronchitis is an ongoing exacerbation where coughing lasts for a three month period, two years in a row.

Smoking is the number one risk factor of COPD. Fifteen to twenty percent of smokers have been diagnosed with COPD. Yet, ten to fifteen percent of individuals with COPD never smoked. These statistics indicate that other variables such as air pollution and genetic composition predispose people to the disease. "No part of the population is safe", said Dr. E. Neil Schachter, Co-Chair of the NY COPD Coalition.

Alpha-1

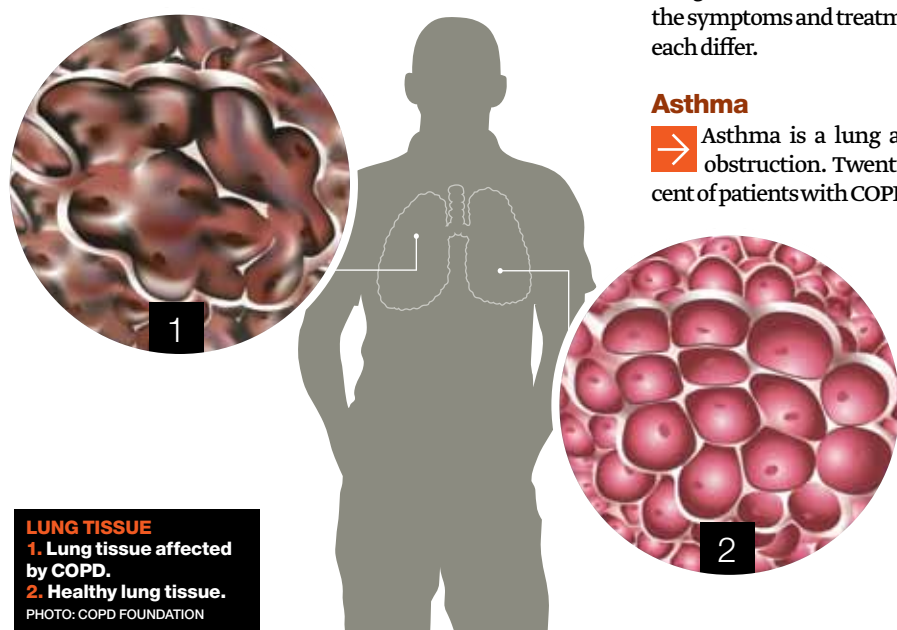
→ One genetic risk factor linked to COPD is the Alpha-1 Antitrypsin protein deficiency disease. Individuals with Alpha-1 Antitrypsin deficiency are more susceptible to lung diseases like COPD. One percent of individuals diagnosed with COPD are also Alpha-1 Antitrypsin deficient.

Lung vulnerability among patients with COPD varies. Isolating the underlying genetic similarities between COPD patients is vital to effectively diagnosing and treating patients with COPD. Ongoing research on the genetic components of COPD is conducted at Columbia University in New York. Researchers are investigating the potential impact of race, gender and ethnicity on COPD.

The COPD gene study is a genetic epidemiological study. Biostatisticians and molecular geneticists are working to isolate the disease-related genes implicated in COPD. Data collected will provide early detection markers of COPD. Results from the study will lead to individualized treatment plans that improve quality of life and decrease exacerbations for patients.

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LUNG TISSUE

1. Lung tissue affected by COPD.

2. Healthy lung tissue.

PHOTO: COPD FOUNDATION

Have emphysema, chronic bronchitis or COPD? Interested in finding out more about your lung health?

Columbia University is recruiting people with these lung problems for important research studies funded by the National Institutes of Health. One study is a clinical trial of fish oil in COPD. Another is looking at heart-lung interactions and includes a CT scan of the lungs. Reimbursement is up to \$250.

If you have – or think you might have – these lung problems, are age 40 years or older, and have smoked cigarettes at some point in your life, please contact us at **212-305-6859** or **copdstudies@columbia.edu** to find out more about these studies.



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NEWS

Combat COPD in the city

TIP
2
KNOW THE RESOURCES AVAILABLE TO YOU

The Learn More Breathe Better Campaign of the National Heart Blood and Lung Institute (NHBLI) is the first of its kind to launch a national COPD public awareness initiative.

The Learn More Breathe Better Campaign is the first wave of increasing national awareness of COPD in a targeted way.

The goal of the Learn More Breathe Better Campaign is to join people from across the country in an effort to combat the COPD epidemic in the United States.

People who are interested in learning about COPD symptoms and treatment can simply access the website free of charge and find a host of important resources on health care providers, treatment options and local treatment centers for COPD in their local area.

Medical professionals, health-care providers, family members and anyone who is affected by COPD can share information on caring for someone with COPD. The Learn More Breathe Better campaign provides helpful



JOURNEY TO THE CENTER OF THE LUNG. The COPD Shuttle, Journey to the Center of the Lung is a 20 seat, state of the art mobile motion simulator launched by the COPD Foundation in May 2010. PHOTO: COPD FOUNDATION

tools and resources for users.

Over the past two years, the campaign worked with websites around the country to develop workshops and activities needed at the state level for effectively responding to COPD. The Learn More Breathe Better Campaign brings facts to community centers and to local practitioners who can utilize materials locally for comprehensive care of individuals with COPD.

The New York COPD Coalition is a group of key strategic partners that are working to address the COPD epidemic in New York State. The NY COPD Coalition will use research, public policy, educational programs and public health care systems to ease

the burden of families that are strained by COPD.

The NY COPD Coalition is shedding light on the disease and developing strategies to cope with it. The Coalition uses the COPD Shuttle, a 20 seat motion simulator used to mimic the infrastructure of the lung. The Shuttle travels from city to city raising awareness of lung function and COPD.

“The outlook for COPD isn’t as bleak or as depressing as it use to be. We have rehabilitation and medication that can improve the quality of life of most of these patients” said Dr. Neil Schachter, Co-Chairman of the COPD Coalition.

The NY COPD Coalition has partnered with the U.S. COPD

Coalition on a comprehensive five year action plan to develop strategies in COPD care. “Resources for COPD are not known by patients or practitioners”, said Schachter.

Improving the quality of life for people with COPD is one of the main endeavors of the NY COPD Coalition. Identifying effective treatment methods, improving diagnoses and expanding the scope of COPD surveillance and research will prepare the State of New York to deal with COPD. Effectively managing COPD in New York is possible with help from the NY COPD Coalition.

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DON'T MISS!

Understanding bronchiectasis

➔ Bronchiectasis is a lung condition when damaged airways slowly lose the ability to clear out mucous build up in them. Bacteria grow as the mucous continues to clog the airways which lead to repeated lung infections. With every new lung infection, the condition worsens. Mucous build up in the airways prevents oxygen flow to vital organs in the body. Bronchiectasis is characterized by a daily cough that produces large amounts of spit where mucous or blood may be present. People with bronchiectasis may experience shortness of breath, wheezing, or chest pain. Today, non-cystic fibrosis bronchiectasis remains a serious health concern for adult’s age of onset between 60 and 80 years-old.

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INSIGHT



MEMBERS OF THE DRIVE4COPD.COM RACE TEAM ALL BRING MOTIVATION TO THE FIGHT AGAINST COPD

**Michael Strahan**

■ Legendary New York Giants defensive end Michael Strahan plans to be just as relentless in getting out the word on COPD as he was in 15 years spent sacking NFL quarterbacks. "People might say 'I don't have symptoms or I only smoked a little,' but the fact is you should get tested. It takes five minutes." Michael's Uncle Bud suffered with COPD. "I watched my whole family deal with it. I just wish I could have met him earlier."

**Patty Loveless**

■ Grammy Award-winning country music star Patty Loveless' involvement in Drive4COPD is inspired by memories of her sister Dottie who died 14 years ago of emphysema. "I was so in awe of her, she was such an amazing singer and dancer. And at the end she was so weakened by COPD she struggled to pull herself up in bed." Loveless wrote and recorded the COPD campaign song "Drive" in honor of Dottie, who died at 48. "I want people to know that COPD doesn't just affect the elderly. I wish Dottie could hear it."

**Bruce Jenner**

■ Bruce Jenner knows a thing or two about staying fit—now he's trying to get the message out to anyone who might be struggling with COPD. "You don't need to run a decathlon," says Jenner, who won a 1976 Olympic Gold Medal doing just that. "Pay attention to what you eat. Get some exercise and spend five minutes right now taking the online COPD test." Jenner watched his wife's grandparents die of COPD. "The key is getting on this early before you lose lung capacity. If you catch it you can manage it."

**Danica Patrick**

■ Lightning quick reflexes behind the wheel helped make Danica Patrick the first woman to win an Indy car race. Now she's looking to bring that same sense of urgency and awareness to the millions of COPD sufferers who may not realize how debilitating this disease can be, and how quickly it can take hold. "I know this is a race against time," said Patrick, who saw her grandmother die from COPD. "People need to do a quick read of their health. I got involved with Drive4COPD because I want to make that happen."

**Jim Belushi**

■ In 30+ years as a performer, Jim Belushi knows the trick to comedy and drama alike: make it real. An earthy, real guy exuberance was his trademark in the hit series *According to Jim* and now he's bringing that same blend of manic seriousness to Drive4COPD. "I saw what COPD did to my father's health and now my aunt. Let this disease take hold and it will just tear you apart."

JOSEPH KELLY

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NEWS

COPD AND ASBESTOS-RELATED DISEASE

Asbestos is a naturally occurring mineral that was widely used throughout New York City in private, public and industrial buildings.



ASBESTOS FIBERS look like cotton but are much rougher to the touch and even a small exposure puts you at high risk for lung cancer and mesothelioma. PHOTO: ASBESTOS.COM

Exposure to asbestos is known to cause a range of debilitating lung diseases that New Yorkers should be aware of to understand the importance of avoiding asbestos exposure.

According to current research, the connection between asbestos and Chronic Obstructive Pulmonary Disease (COPD) is not as clear as the connection between asbestos and other lung diseases. However, scientific studies have found a statistically significant association between COPD and exposures to toxic materials such as asbestos and silica.

The American Lung Association has reported exposure to asbestos can easily aggravate a previously existing case of COPD. In some cases, asbestos exposure may even be one of the factors that cause or contributes to the development of the condition.

Asbestos is not known to cause COPD directly, but the toxic mineral is known to directly cause asbestosis, lung cancer and mesothelioma cancer. The latter is caused almost exclusively by asbestos exposure and most commonly affects the lining of the

lungs. In the United States, approximately 2,000 to 3,000 cases of mesothelioma are diagnosed each year. Mesothelioma has a long latency period of 20 to 50 years before symptoms arise, which usually results in a late diagnosis. While the cancer is primarily

treated with surgery, chemotherapy and radiation therapy, experimental procedures such as immunotherapy, photodynamic therapy and gene therapy are also being used to treat mesothelioma patients in clinical trials.

Mesothelioma is an especially aggressive cancer and although no cure has been found, numerous studies are constantly finding new combinations of therapies to treat the disease. With increasing reports of mesothelioma survivors and growing research breakthroughs, much hope is available to recently diagnosed patients looking to improve their life expectancy.

For more information visit Asbestos.com.

MICHELLE WHITMER
editorial@mediaplanet.com

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For example, you may not have realized it, but if you are a smoker and were occupationally exposed to asbestos, you will have a 50 to 100 times increased risk of getting lung cancer.

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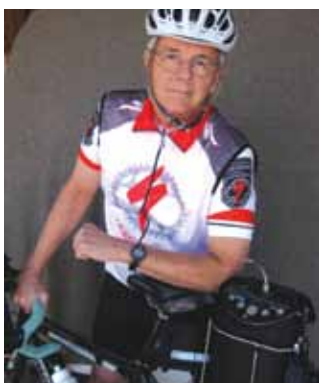


TIP
3
UTILIZE
TECHNOLOGY

Biking to tell the world

HOW I MADE IT

Mark Junge, biking along Route 1 south of Daytona, Florida, seems like any other health-conscious senior citizen getting some exercise in the beautiful Florida sunshine.



Mark Junge
Oxygen-dependent cyclist

Except Mark is headed for Key West—400 miles away. And he never goes anywhere—not on his bike, not out for a walk, not for a ride in the car or to bed at night—without being connected to a source of oxygen.

Mark, 67, has Chronic Obstructive Pulmonary Disease (COPD); his lungs cannot process enough

oxygen. It's estimated that more than 24 million Americans have COPD—half of them undiagnosed. Many were smokers. Many others are just like Mark: an avid outdoorsman back home

in Cheyenne, Wyoming, he has a condition that causes blood clots in his lungs.

"I was depressed. I saw my life as lying in a recliner attached to a piece of plastic. And then I decided: I will not leave the planet this way."

Two years after his diagnosis, Mark biked from San Francisco to New York. A year later: New York to Newfoundland. Then from New York to Charleston. And now, he's going as far south as you can go in the U.S.

"My message to people with COPD is: Reclaim your life. Don't stop. The technology exists to let you do just about anything you want to do. Get started using it now."

JOSEPH KELLY
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NEW OPTIONS IN OXYGEN CONCENTRATORS

Portable Oxygen Concentrators (POC) use electronics to provide oxygen-rich air. There is no stored oxygen tank. But there are different kinds of POCs:

Pulse-flow POCs deliver oxygen on demand whenever you breathe through your nose. Small, light-weight and energy-efficient—they are ideal for travel. But you have to remember to breathe—not always easy at night or while exercising.

Continuous flow models deliver a steady stream of oxygen all the time. Many people use them at home

when they are sleeping.

More POCs offer both pulse and continuous modes. And the trend to smaller, lighter, more energy-efficient POCs is likely to continue, according to Ron Richard CEO of SeQual, Technologies Inc., a POC manufacturer: "The military needs tankless models that won't explode, can fit in backpacks and last longer in the field. Also the smaller POCs are opening the door to having these units as standard equipment in home care and next to defibrillators in airports and other public locations."

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BRINGING OXYGEN ONBOARD AIRLINES

If you need oxygen, you can now bring it on the plane with you: passengers in the U.S. can choose from among 11 approved

Portable Oxygen Concentrators (see the list at (www.faa.gov/about/initiatives/cabin_safety/portable_oxygen/).

Congratulations

2010 COPD Foundation Annual Awards and Recognition Benefit

The COPD Foundation
would like to congratulate the following 2010 Honorees:

- Senator Michael Crapo
- James Kiley, PhD
- John Leaman
- Ruth M. Tal-Singer, PhD
- Gerard Turino, MD
- The DRIVE4COPD Campaign
- The Shell Foundation

Would you like to congratulate an honoree?

You can place a congratulatory ad in the event program. All Honorees will be recognized for their achievements on December 9, 2010 at the Hudson Theater in New York City.

For more information on attending this event or to place an ad, please contact Brandi Suttles at 1-866-731-2673 x451 or bsuttles@copdfoundation.org.

If you would like to donate to the COPD Foundation there are a number of ways. You can donate online at www.copdfoundation.org or over the phone toll-free 1-866-731-2673 ext. 246.



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Question 1:
What are
some tips you
can offer for
preventing
COPD?

COPD can most easily be prevented by stop smoking cigarettes or never start smoking cigarettes, as well as avoiding exposure in your occupation to chemical fumes or dust. The majority of cases are directly related to cigarette smoking.

COPD is a condition that develops due to prolonged exposure to various pollutants. However, the condition can be managed by avoiding triggers and exposure to pollutants such as cigarette and cigar smoke, second-hand smoke, dust, environmental contaminants and strong fumes, all of which can irritate the lungs. Additionally, stay indoors as much as possible when the outdoor air quality is poor, try to avoid crowds during flu season and get an annual flu shot.

The best way to prevent COPD is to never smoke and the best way to slow progression of COPD if you do smoke is to stop. Having said that, it is worth stressing that while most people with COPD have a smoking history (some 80 percent), 20 percent of folks with COPD in this country never smoked and only 15-20 percent of smokers develop significant COPD suggesting that other factors, genetic or environmental must play roles. So limiting exposure to environmental risks whether smoking, biomass fuels, and occupational dusts.

In the developed world, tobacco smoking is by far the leading cause of COPD. First and foremost, don't smoke, and avoid being in closed spaces with those who are smoking. It's also important to avoid smoke from fires, dust, and other forms of pollution. If you work in this sort of environment, talk to your company safety officer, try to improve the ventilation in your work area, and consider wearing a mask designed to block particulate pollution.

Question 2:
What is your
industry
doing to
support COPD
Research?

The industry of Medical Device Manufacturers of Respiratory Equipment continue to introduce new equipment to improve disease management and oxygen therapy for COPD patients and COPD researchers.

The industry needs to focus on oxygen and respiratory technologies that allow patients to remain active, mobile and part of society. A large oxygen tank and cart is no longer an acceptable form of oxygen therapy given the technological advancements made in recent years. The industry must continue to adapt, change and develop new technologies that meet patient and doctor demands, allowing patients to maintain a high quality of life.

I have helped found and now serve as chairman of the board of the COPD Foundation, a non-profit whose mission is to improve the quality of life of those who suffer from this disease through research, education, early diagnosis, and enhanced therapy. The ultimate hope is that these actions will lead to better treatments and some day lead to a cure.

The pharmaceutical industry invests heavily in understanding the processes that lead to lung injury, as well as finding new drugs to treat the inflammation that is COPD's root cause. We also strive to discover treatments designed to relieve COPD's symptoms and prevent its complications. Finally, pharmaceutical companies work hard to produce drugs that help patients overcome their addiction to smoking. All this is done both through the industry's own scientists, as well as via partnerships with academic research centers and government health agencies.

Question 3:
What are
common mis-
perceptions
when
diagnosing
COPD?

- **Patients may** misunderstand or minimize symptoms such as fatigue, dyspnea, cough. They may neglect to mention these symptoms to the physician.
- **Misperception and denial** are significant barriers to diagnosis and management.
- **Symptoms may** be misattributed to "asthma" or "getting older."

The most common misperception is that COPD is caused only by smoking. While there are COPD sufferers who smoke or have smoked, other causes include exposure to second-hand smoke, occupational dust and chemicals, and air pollution. Asthma, emphysema, genetic factors, and an increase in the intensity of respiratory infections also contribute to COPD. Healthcare professionals need to look deeper into the causes of COPD to ensure they are diagnosing the condition earlier for better long-term outcomes.

The perception has been that COPD is a disease of the elderly. That is not true. Most with COPD are middle aged and it is as common as asthma and diabetes in folks aged 40-60. The perception that COPD is a disease of men is not true. Since 2000 more women have been diagnosed with, hospitalized with and died with COPD than men. The perception has been that COPD is a poorly treatable or untreatable disease. That too is untrue. COPD is almost always preventable. COPD is almost always treatable. But to treat it you need to diagnose it.

All of us have misconceptions regarding chronic lung disease. Many smokers assume that if they are not experiencing symptoms, they are not suffering lung injury. Waiting for symptoms may mean permanently losing lung function. And while smoking is a critically important cause of lung disease, it's not the only one. If you don't smoke, don't assume you're immune to important lung disorders. So if you have shortness of breath or a persistent cough, tell your doctor. Speak openly and don't be shy.

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