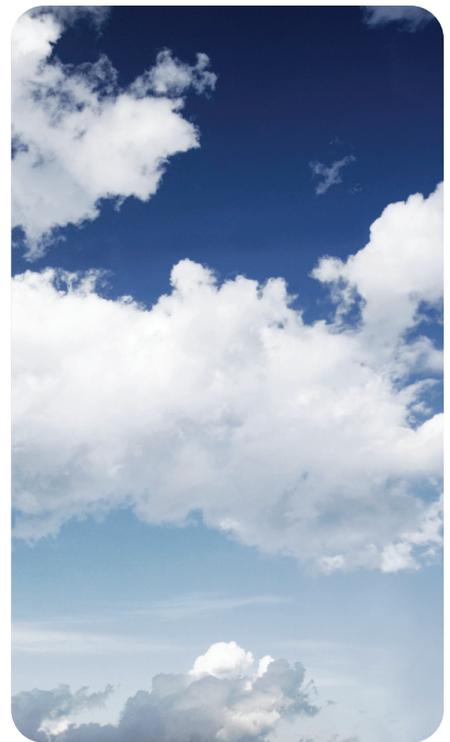
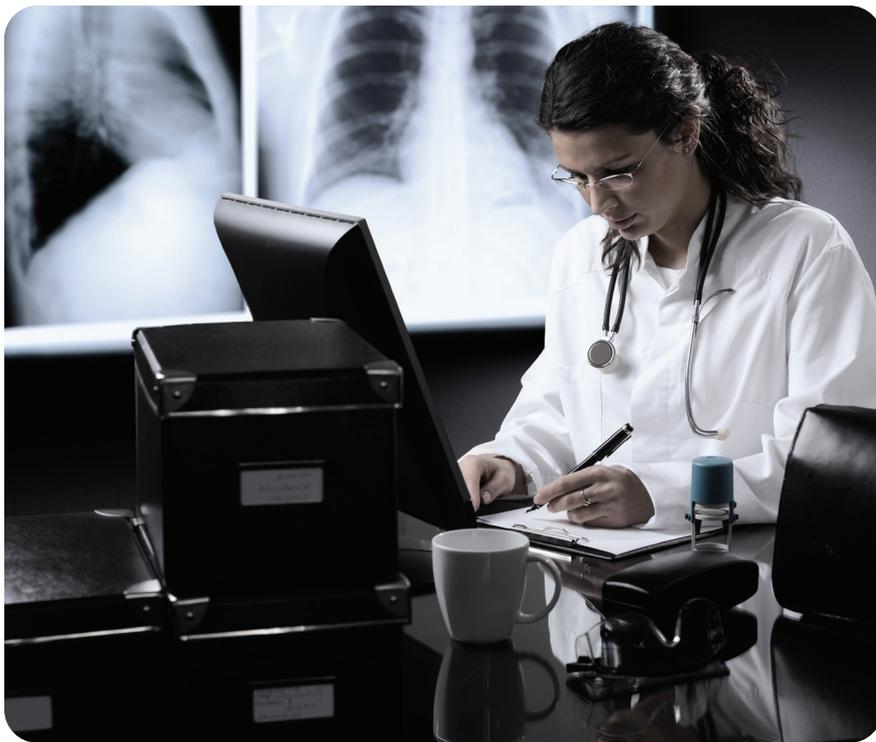


STRATEGIC PLAN TO ADDRESS COPD IN CALIFORNIA



November 2012

Dear Friends,

The American Lung Association in California is proud to have convened the first California COPD Summit in Los Angeles during the summer of 2008. The *Strategic Plan to Address COPD in California* is a product of that Summit and the attendees who represented a diverse array of stakeholders from all across California who came together to address COPD. Since then, COPD has moved from fourth to third place as the leading cause of death in the United States so our work is more urgent than ever.

To address this urgent and growing health crisis in California, the American Lung Association in California and the California Thoracic Society have updated the plan to reflect current data and recommendations for the prevention, diagnosis and treatment of COPD. The *Strategic Plan to Address COPD in California* is critical to focusing public attention on this important lung disease, from which more than 12 million Americans suffer and millions more remain undiagnosed. Our hope is that the Strategic Plan will provide an opportunity for all stakeholders – physicians, health care providers, hospitals, insurance providers, pharmaceutical companies, employers, governments, researchers and patients – to work toward preventing COPD, improving the diagnosis, treatment and care of the disease, as well as raising the quality of life for those who have it.

If we are to achieve these goals, we must work hard together to implement the recommendations of the *Strategic Plan to Address COPD in California*. This achievement will require work by every facet of society – from government to private employers, to giant medical systems to individual health care providers, to people living with COPD and those who care for them.

We ask that you please read the *Strategic Plan to Address COPD in California* and get involved!

Sincerely,



Jane Warner
Chief Executive Officer
American Lung Association in California



Karl Van Gundy
President
California Thoracic Society

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Goals and Objectives Summary

Goal Area 1: Prevention

Prevent the development and slow the progression of COPD among Californians.

OBJECTIVE A: Reduce exposure of Californians to tobacco.

OBJECTIVE B: Reduce the exposure of Californians to ozone and particulate matter pollution.

OBJECTIVE C: Reduce the exposure of California workers to inhaled vapors, gases, dusts, and fumes associated with the development of COPD.

OBJECTIVE D: Minimize the risk to COPD patients from disasters and climate change.

Goal Area 2: Quality of Care

Improve the quality of care for those with COPD.

OBJECTIVE A: Promote the use of the COPD Guidelines.

OBJECTIVE B: Promote the use of written COPD management plans.

OBJECTIVE C: Promote pulmonary rehabilitation.

Goal Area 3: Public Health Infrastructure and Advocacy

Enhance the capacity of the public health system and local advocates to reduce the burden of COPD in California.

OBJECTIVE A: Support the development, funding, and staffing of a state public health program focused on COPD.

OBJECTIVE B: Build the capacity of the California COPD Coalition.

OBJECTIVE C: Develop and support a network of local community partner coalitions to increase awareness and understanding of COPD among patients, health care providers, local policy makers, and the general public.

OBJECTIVE D: Enhance the capacity of COPD patients and patient groups to advocate for health care that is consistent with COPD management guidelines.

OBJECTIVE E: Enhance the capacity of COPD patients and patient groups to advocate for increased investment in COPD prevention.

Goal Area 4: Surveillance

Assess the scope of COPD in California through the creation of a statewide surveillance system.

OBJECTIVE A: Establish infrastructure for the collection and analysis of COPD data in California.

OBJECTIVE B: Disseminate COPD-related data to stakeholders throughout California.

Goal Area 5: Research

Leverage California's unique resources to maximize research into COPD prevention, diagnosis, and treatment.

OBJECTIVE A: Augment California's research infrastructure.

OBJECTIVE B: Organize and disseminate the latest research findings.

Goal Area 6: Public Education and Awareness

Increase public awareness and understanding of COPD.

OBJECTIVE A: Utilize mass media opportunities to increase the general public's awareness of chronic lung disease, particularly the term COPD, its cost, and its risk factors.

OBJECTIVE B: Collaborate with the tobacco control community to increase public awareness of COPD and educate smokers about the disease.

OBJECTIVE C: Improve patient understanding about COPD management and prevention.

OBJECTIVE D: Improve awareness of COPD among policy-makers.

Chronic Obstructive Pulmonary Disease (COPD) Overview

What is COPD?

COPD is one of the most significant public health issues in the United States today. COPD is a preventable and treatable disease, and is currently the third leading cause of death in the nation.¹ COPD refers to two related diseases that cause airflow obstruction and breathing-related problems: *emphysema* and *chronic bronchitis*. *Chronic bronchitis* is the long-term swelling and thickening of the tubes that make up the airways – bronchi and bronchioles.² Excessive mucus is produced and causes obstruction in the airways and coughing. Over time, the lungs become more sensitive to the irritation and airflow in and out of the lungs becomes more difficult. *Emphysema* occurs when the air sacs, or alveoli, are damaged.² This damage decreases the exchange of oxygen and carbon dioxide, which results in the feeling of shortness of breath.³ The damaged air sacs can also create large spaces in the lungs where air can become trapped. In both chronic bronchitis and emphysema, the diseased lungs lose elasticity and do not expand and contract as well as healthy lungs, making breathing difficult. People living with COPD usually have a combination of both chronic bronchitis and emphysema. COPD almost always gets worse over the long term, and there is no cure for COPD. However, people can keep their COPD in control by taking proper steps.

How big of a problem is COPD in our society?

Unlike the other leading causes of death that are on the decline, the prevalence of COPD continues to rise, and is a major cause of disability. About 24 million Americans have COPD, but it is estimated that fewer than half have been diagnosed or know they have the disease.⁴ Nationally, COPD kills more than 125,000 Americans each year⁵ – that equals one death every four minutes. In addition, COPD is expensive, costing the nation an estimated \$42.6 billion in 2007.⁶ An estimated \$832.9 billion in direct medical costs will be spent over the next 20 years.⁷

Applying age-specific national COPD prevalence estimates to California's population, an estimated 1,178,481 Californians (3.1%) have been diagnosed with chronic bronchitis and 491,670 (1.3%) have been diagnosed with emphysema.⁸ In California, COPD is the fourth-leading cause of death, claiming the lives of 12,905 Californians in 2009.⁹ In 2006, California's Office of Statewide Health Planning and Development (OSHPD) reported 46,407 hospital discharges associated with COPD, amounting to an estimated \$1.34 billion in medical costs.¹⁰

In spite of the huge health burden of COPD, it remains among the most underfunded of major diseases by the National Institutes of Health.¹¹ In 2008, COPD ranked 130 out of all disease entities in research funding from the National Institutes for Health.¹²

Causes

The most common cause of COPD is smoking, and is responsible for approximately 80 to 90 percent of COPD cases.⁹ Environmental exposure to chemicals, dust, fumes, biofuels, high levels of air pollution, and secondhand smoke can also lead to the development of COPD.¹³ Occupational exposure to those irritants is also common in industries such as coal mining, rock mining, and welding.¹⁴ These exposures put many at risk for development or exacerbation of COPD. Occupational exposures may contribute to and/or cause COPD in 10 to 20 percent of individuals with the disease.¹⁵

Additionally, a genetic condition called alpha 1-antitrypsin (AAT) deficiency can lead to the development of COPD. *Alpha-1 antitrypsin deficiency-related emphysema* is caused by the inherited deficiency of a protein called alpha-1 antitrypsin, or alpha-1 protease inhibitor. At least 100,000 people in the United States may have alpha-1 antitrypsin deficiency. Without the AAT protein, emphysema is almost inevitable. This deficiency is responsible for five percent or less of the emphysema in the United States.¹⁶

Symptoms

The first signs of COPD can be very subtle. A person may begin to experience breathing problems during daily activities like climbing stairs, walking at their former pace, bathing, cooking, or cleaning. Common symptoms include a chronic wet cough, shortness of breath, excess mucus production, wheezing, and chest tightness. Often, people do not realize that they have COPD as it develops slowly over time. Individuals may unconsciously reduce certain activities in order to accommodate their breathlessness.^{17,18}

Diagnosis

Everyone at risk for COPD – especially those with exposure to tobacco or occupational hazards¹⁹ who has cough, mucus, or shortness of breath, should have spirometry testing performed.^{19,20} Spirometry is a non-invasive breathing test that evaluates how well a patient's lungs are working and can detect COPD before symptoms become severe. This test is done with a device called a spirometer, which measures both the amount of air and the speed at which a person can blow it out of his or her lungs. The test is able to detect very small changes in breathing that are not apparent to the patient. The tests take only a couple of minutes, do not involve needles, are not painful, and do not require patients to remove any clothing. For individuals already diagnosed with COPD, especially those younger than 50 years old, genetic testing for alpha-1 antitrypsin deficiency is recommended.¹⁶ Alpha-1 Antitrypsin testing may require only a finger prick.

Treatment

The single most important action a person diagnosed with COPD or at risk for COPD can take is to quit smoking. Smoking cessation alters the disease course regardless of the duration and severity of the disease.²¹ Smoking cigarettes accelerates COPD, and also minimizes the effects of established therapies. Smoking cessation is the only preventive measure that can increase survival rates for COPD.²²

People living with COPD are at greater risk for respiratory infections. Thus, prevention of infections, or quick treatment, is necessary for proper COPD management. All patients with COPD should receive an annual flu shot in advance of flu season.^{19,20} All COPD patients should receive the pneumococcal vaccination. COPD patients 65 years of age or older should receive a second dose of the vaccine if they received their first dose at least five years previously and were less than 65 years old at the time of the initial vaccination.²³

Most people with COPD take medications on a regular basis in order to improve breathing. Other medications are used on an as-needed basis to decrease shortness of breath. Medications prescribed for people with COPD fall into one of three groups: 1) bronchodilators, medication that are usually inhaled and are designed to open up the patient's airways; 2) steroids, which reduce inflammation in the airways; and 3) antibiotics, which treat infections associated with exacerbations. For patients with alpha-1 antitrypsin deficiency, data suggest that supplementation of the missing protein may slow the rate of loss of lung function and improve survival.^{24,25}

Oxygen therapy is a treatment used for patients who have severe COPD and low bloodstream oxygenation. This treatment can improve exercise capability, sleep, and cognitive performance, as well as decrease the risk of death for patients with chronic respiratory failure.²⁶ Small, lightweight portable oxygen units allow patients to continue employment and fully participate in recreational activities away from home, including travel.¹⁹

Pulmonary rehabilitation is an individually designed program of care for patients with COPD. It is designed with the intent to maximize functioning and to optimize physical and social performance. The goals of pulmonary rehabilitation are to reduce symptoms, improve quality of life, and increase participation in daily activities. Research has demonstrated that pulmonary rehabilitation decreases shortness of breath and improves function and quality of life scores.²⁷ Emerging research also shows that pulmonary rehabilitation may reduce hospitalizations and health care costs.²⁸

Parts of this section were taken from the State Plan for Addressing COPD in Illinois. We are grateful to the Illinois COPD Coalition for their support.

Development of the *Strategic Plan to Address COPD in California*

Stakeholders representing an array of interests in COPD convened a COPD Summit in June 2008 in Los Angeles, California. Summit attendees self-selected into four working groups: Data and Surveillance, Education and Awareness, Research, and Treatment and Diagnosis. The working groups generated recommendations that were utilized in the development of the several sections in this *Strategic Plan*. These recommendations were later compiled into an outline, which underwent several revisions based on group feedback over the subsequent months.

The impetus for the update of the *Strategic Plan* was the change in ranking of COPD from fourth to third leading cause of death in the United States, which provided an opportunity to review the data points and update relevant research and strategies. Several of the original writers and editors reviewed and provided valuable feedback for each section. The plan represents a 5-year timeframe for action.

The final document has six sections, each corresponding to a goal area:

- **Prevention**
- **Quality of Care**
- **Public Health Infrastructure and Advocacy**
- **Surveillance**
- **Research**
- **Public Awareness and Education**

Each section follows the same format:

- **Goal Area and Goal Statement**
- **Rationale:** Explains why the goal is necessary and gives background and supporting evidence about the approach outlined in the objectives and strategies.
- **Objectives:** Objectives describe specific results to be achieved. Objectives are lettered.
- **Strategies:** Strategies under each objective describe the manner in which the objective will be achieved. Strategies are numbered.
- **Potential Partners:** Organizations, agencies, and other stakeholders who should be most actively involved in working to achieve an objective.
- **Recommended Performance Measures:** When useful, potential opportunities to measure progress toward achieving an objective are included.

The California COPD Coalition

The California COPD Coalition is a group of stakeholders working to improve the health and quality of life of individuals affected by COPD in California. The Coalition formed during the process of creating the *Strategic Plan to Address COPD in California*. Membership in the California COPD Coalition is open to all interested organizations and individuals. The American Lung Association in California currently coordinates the California COPD Coalition. If you are interested in joining, please call your local American Lung Association office at 1-800-LUNG-USA.

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Goal Area I: Prevention

Goal Statement: Prevent the development and slow the progression of COPD among Californians.

Background and Rationale:

The Global Initiative for Chronic Obstructive Lung Disease, or GOLD, emphasizes that COPD is a preventable and treatable disease.^{19,20} The prevention of COPD is the focus of this section, while treatment of COPD will be covered elsewhere.

In order to develop effective strategies to prevent COPD, we must first consider the risk factors for COPD. Risk factors include both host factors and environmental exposures, with COPD usually arising from an interaction between the two types of factors.²⁹ The most well documented host factor – a rare, inherited deficiency of alpha-1 antitrypsin – is not modifiable. However, environmental exposures can be modified, and therefore make excellent targets for COPD prevention. Major environmental risk factors for COPD are tobacco smoke, heavy exposure to occupational dusts and chemicals, and indoor and outdoor air pollution.²⁹ Individuals may be exposed to a variety of different types of inhaled particles over their lifetime. Each type of particle may contribute a different weight to the risk, with the total risk dependent on the weighted sum of the inhaled exposures.²⁰

Cigarette smoking is the most commonly encountered risk factor for COPD.^{19,20} Approximately 80 to 90 percent of COPD is attributable to smoking, depending on which definition of COPD is used^{13,30} and smoking is estimated to be responsible for at least 75 percent of COPD deaths.³¹ The risk for COPD in smokers is dose-related. Passive exposure to cigarette smoke may also contribute to COPD by increasing the total burden of inhaled particles and gases.¹⁹ Smoking cessation programs are a “key element of COPD prevention, as well as an important intervention for patients who already have the disease.”^{19,20}

California is a leader in fighting the harmful effects of tobacco with a statewide smoking prevalence rate of 12.1% compared to the national average of 19.3%.³² In rural regions of the state however, the prevalence is significantly higher with smoking rates as high as 21%.³³ The California counties with the highest smoking rates are all rural counties: Tuolumne, Butte, Calaveras, Humboldt, and Merced. In addition, according to the Lung Association’s *State of Tobacco Control 2012 – California Local Grades* report, 102 out of 121 rural communities received an F grade for failing to enact strong policies for smokefree outdoor environments, smokefree housing, and reducing sales of tobacco products.

The American Lung Association’s 2012 health disparity report, *Cutting Tobacco’s Rural Roots: Tobacco Use in Rural Communities*, found that people living in rural communities are more likely to use tobacco and have especially high rates of smokeless tobacco use. Rural Americans also are more likely to be exposed to secondhand smoke and less likely to have access to programs to help them quit smoking. Rural youth also are more likely to use tobacco and to start earlier than urban youth, perpetuating the cycle of tobacco addiction and death and disease.

Figure 5: Smoking Prevalence in California, 2008



Data source: California Tobacco Survey, 2008
* Means that a regional prevalence is used

There are many organizations working to reduce tobacco use in California and to support policies that will increase protections against secondhand smoke exposure, focusing on adoption of comprehensive smokefree outdoor public place and multi-unit housing ordinances. The California Department of Public Health's California Tobacco Control Program (CTCP) administers and coordinates the tobacco control efforts of 61 local health departments, hundreds of trained and experienced public health workers, thousands of adult and youth volunteers, approximately 40 community-based organizations, a statewide media campaign, a tobacco cessation helpline, and statewide technical support services. The California Tobacco Control Program also partners with non-governmental organizations and supports local tobacco control efforts. The CTCP's comprehensive nature results from the combined efforts of the California Department of Public Health's Tobacco Control Branch, the University of California's Tobacco Related Disease Research Program, and the California Department of Education's Safe and Healthy Kids Program Office Tobacco Use Prevention Education Program.

Reducing access to tobacco products requires the passage of strong local tobacco retailer license laws and zoning laws that restrict the location and density of tobacco outlets. The administration and enforcement of these laws can be covered by fees paid by tobacco sellers.

Occupational exposures to vapors, gases, dusts, and fumes are an underappreciated risk factor for COPD.^{19,20,35} Approximately 15 percent of COPD is work-related.^{14,36} Associations between COPD and occupational exposures have been observed for coal miners, hard-rock miners, tunnel workers, concrete-manufacturing workers, and non-mining industrial workers.¹⁴ Exposure controls such as elimination, engineering controls, diesel filters, administrative controls, and personal protective equipment are strategies to prevent work-related COPD.³⁵

Indoor air pollution is a risk factor for COPD – especially pollution from biomass fuels used in cooking and heating in poorly ventilated dwellings, as may occur in substandard housing or with older wood stoves.

Exposure to outdoor air pollution, specifically ozone and particulate matter, is associated with worsening pulmonary function in COPD patients and increased emergency department visits and hospitalizations for COPD.³⁶ Ozone is capable of causing inflammation in the lung at lower concentrations than any other gas. Such an effect would be a hazard to anyone with heart failure and pulmonary congestion, and would worsen the function of anyone with advanced lung disease.³⁷

Particle pollution - especially fine particles - contains microscopic solids or liquid droplets that are so small that they can get deep into the lungs and cause serious health problems. Numerous scientific studies have linked particle pollution exposure to a variety of problems, including increased respiratory symptoms, such as irritation of the airways, coughing, or difficulty breathing; development of chronic bronchitis; and premature death in people with heart or lung disease.³⁸

The role of outdoor air pollution in causing COPD is unclear, however.²⁰

According to the U.S. Centers for Disease Control and Prevention, “public health programs that focus on reducing total personal exposure to tobacco smoke, occupational dusts and chemicals, and other indoor and outdoor air pollutants are critically important” to prevent COPD.³¹

Disaster Preparedness and COPD

In the event of a disaster such as earthquake, storm, or wildfire, patients with lung disease may be at increased risk due to loss of access to electrical power and/or oxygen supply. Emergency response plans must address the unique needs of COPD patients; medical professionals must also be prepared for these events in order to minimize the threat to COPD patients and mitigate their effects. COPD patients who are prepared in an emergency can become more independent and build resilience during a disaster.

Global Warming and Respiratory Health

Heat waves and higher temperatures caused by global warming will produce higher ozone concentrations, and lead to increased risk for wildfires emitting smoke and soot, increased pollen and increased dust from decertification.³⁹ All of these factors can lead to increased burden of disease and premature deaths, particularly in patients with chronic lung disease. A January 2012 report by the American Thoracic Society: *An Official American Thoracic Society Workshop Report: Climate Change and Human Health* provides recommendations to address the global threat to respiratory health posed by climate change. The report states that evidence is increasing that climate change does drive respiratory disease onset and exacerbation as a result of increased air pollution, desertification, heat stress, wildfires, pollens, molds, and infectious agents.³⁹

In California, where 90 percent of residents live in areas with poor air quality, there is a need for greater awareness and research of the impacts of global warming on patients with lung disease so that medical and health professionals can advocate for policies that will safeguard public health. Many pulmonary physicians and respiratory professionals are not well aware of the fact that climate change has an important impact on their patients.³⁹

OBJECTIVE A: Reduce exposure of Californians to tobacco.

STRATEGIES

- 1:** Encourage COPD patients who smoke to quit by developing and disseminating cessation materials targeted at individuals with COPD and increase access to effective smoking cessation programs.
- 2:** Partner with statewide and local tobacco education and prevention programs to discourage Californians from initiating tobacco use.
- 3:** Partner with statewide and local tobacco control programs, including the American Lung Association in California, to support policy efforts to reduce exposure to secondhand smoke in public outdoor spaces and in multi-unit housing.
- 4:** Partner with statewide and local tobacco control programs, including the American Lung Association in California, to support policy efforts to reduce access to tobacco products by adopting strict tobacco retailer licenses and zoning restrictions on tobacco sellers.

POTENTIAL PARTNERS

The American Cancer Society *Great American Smokeout Program*, the California Smokers' Helpline, the American Lung Association in California and its Center for Tobacco Policy and Organizing, the California Tobacco Control Program, the American Heart Association, pulmonary rehabilitation programs, COPD support groups, patient periodicals, patient-support websites, local tobacco coalitions, and local tobacco education programs.

RECOMMENDED PERFORMANCE MEASURES

- Utilize Behavioral Risk Factor Survey results in order to track the percentage of persons in general and with COPD who report smoking in the past 12 months.
- Utilize Behavioral Risk Factor Survey results in order to track the percent of Californians who report initiating smoking cessation in the past 12 months.
- Measure the percentage of local tobacco prevention coalitions with whom the COPD Coalition is active (attends meetings, writes letters or testifies in support of ordinances) and assess city and county smoke-free ordinances annually.

OBJECTIVE B: Reduce the exposure of Californians to ozone and particulate matter pollution.

STRATEGIES

- 1:** Support the efforts of local, state, and federal air quality agencies to reduce public exposure to indoor particulate matter pollution by promoting the use of properly ventilated and lower-emission heating and cooking units.
- 2:** Support the efforts of local and state air quality agencies to reduce public exposure to ozone and particulate matter pollution by encouraging all Californians, especially those with COPD, to consult the air quality index (AQI) before participating in outdoor activities.

POTENTIAL PARTNERS

California Air Resources Board and local air quality agencies, Healthy Homes Collaborative, COPD support groups, pulmonary rehabilitation programs, COPD patient periodicals, and patient-support websites, US Environmental Protection Agency, and the American Lung Association in California.

RECOMMENDED PERFORMANCE MEASURES

- Measure the number of letters sent by COPD Coalition to promote reductions in ozone and particle pollution.

OBJECTIVE C: Reduce the exposure of California workers to inhaled vapors, gases, dusts, and fumes associated with the development of COPD.

STRATEGIES

- 1:** Partner with occupational health agencies and programs to educate employers *and* employees in high-risk industries and occupations about reducing workplace exposures to vapors, gases, dusts, and fumes. Education points should address the elimination of potentially harmful materials, engineering controls, diesel filters, safe work practices, administrative controls, and the availability and proper use of personal protective equipment for employees.
- 2:** Educate health care providers about occupational exposures associated with the development and exacerbation of COPD. Also, encourage all providers to assess occupational exposures including the use of protective equipment, and evaluate individuals with occupational exposure for COPD or symptoms suggestive of COPD.

POTENTIAL PARTNERS

The Occupational Health Branch of the California Department of Public Health, the California Division of Occupational Safety and Health (Cal/OSHA), the California Thoracic Society, the COPD Educator Institute, and local health care providers.

RECOMMENDED PERFORMANCE MEASURES

- Measure the number of campaigns with whom the COPD Coalition collaborates (writes letters or testifies in support of programs to reduce workplace exposures) and assess the success of the campaigns annually.
- Measure the number of trainings provided to health care providers to educate them on occupational exposures associated with COPD.

OBJECTIVE D: Minimize risks to COPD patients from disasters and climate change.

STRATEGIES

- 1: Develop protocols for managing the unique medical needs of COPD patients during a disaster and extreme events.
- 2: Advocate for policies that reduce emissions of air pollution and greenhouse gases to reduce the public health impacts and threat of climate change.

POTENTIAL PARTNERS

The California Thoracic Society, the American Thoracic Society, California Department of Public Health, and the American Lung Association in California.

RECOMMENDED PERFORMANCE MEASURES

- Guidelines for managing COPD during an emergency will be developed and validated.
- Measure the number of letters submitted and testimony provided to support policies that reduce greenhouse gases.

Goal Area 2: Quality of Care

Goal Statement: Improve the quality of care for those with COPD.

Background and Rationale:

While COPD is a preventable and treatable disease, it is also highly complex. Clinical management of COPD is far from ideal. Two documents provide guidelines for COPD that are recognized worldwide as the primary resources for treatment of the disease: guidelines for diagnosis and treatment are published by the Global Initiative for Chronic Obstructive Lung Disease (www.goldcopd.org), or GOLD,²⁰ and the joint European Respiratory Society (ERS) and American Thoracic Society (ATS) diagnostic and treatment standards (<http://www.thoracic.org/sections/copd/index.html>).^{16,20} Many clinicians, however, are unfamiliar with these resources. Therefore, adherence to these standards is poor.⁴⁰ Hospital readmissions for COPD is becoming a significant problem as well, reflecting a lack of adequate disease management.

Improving adherence to the standard care for COPD can have important implications for patients with COPD. Success with COPD management relies on the commitment of clinicians to guidelines for early and proper diagnosis, as well as appropriate treatment.

For example, the California Association of Physician Groups (CAPG) has the ability to disseminate guidelines and emphasize the need to improve quality of care for COPD patients. CAPG is the advocacy group for the majority of medical groups in California, and has created a program called “Standards of Excellence.” In this program, participating groups select three disease states upon which to focus their quality improvement efforts. Physicians in groups like this one have experience following clinical guidelines and being measured for quality of care. Also, the Managed Care Division of Medi-Cal already has a small COPD collaborative and has made that an area of emphasis for quality improvement.

Several issues continue to limit effective clinical management of COPD. It has been estimated that there are about as many people with undiagnosed COPD as there are with diagnosed COPD.⁴ One study revealed that an initial diagnosis of COPD was made during a hospitalization in nearly one-fifth of COPD patients.⁴¹ Earlier diagnosis of COPD could lead to more timely interventions, including smoking cessation and appropriate pharmacotherapy, and may result in improved quality of care. COPD is often misdiagnosed as asthma, leading to inappropriate treatment and suboptimal patient outcomes – increased awareness of the differences between the two conditions is needed to promote optimal patient management and treatment.⁴² Spirometry testing is the standard for confirming diagnosis of COPD, but few primary care providers have been trained to utilize it. Use of spirometry testing allows practitioners to stage patients for appropriate treatment according to disease severity.²⁰ In addition to spirometry testing, any symptomatic patient would benefit from a complete set of pulmonary function tests, including lung volumes and diffusing capacity to confirm COPD diagnosis.

Comorbidities are common in COPD and should be actively identified because they often complicate the management of COPD.²⁰ The most common comorbidities associated with COPD include cardiovascular disease, asthma, excessive weight loss, anxiety, panic, and depression.^{43,44} In patients hospitalized for other conditions, COPD is the second most common comorbidity, following hypertension.⁴⁵ In one study, COPD patients incurred additional costs of \$3,671 over the two years prior to diagnosis when compared with matched controls.⁴¹ Better identification of comorbid conditions would improve health and save money.

Quality metrics (i.e., HEDIS measures) defined and promulgated by the National Commission on Quality Assurance (NCQA) for asthma and diabetes have led to improved care and outcomes for those two diseases. NCQA also offers recommendations on COPD; adherence to these metrics promises similar improvement. The first NCQA measurement for COPD is the use of spirometry – specifically, the percentage of patients age 40 years and older with a new diagnosis of COPD who received spirometry testing to confirm the diagnosis. Spirometry is a relatively inexpensive test and is considered the standard of care by GOLD, ATS, and ERS for confirming diagnosis of the disease. NCQA has made spirometry a core measure of their accreditation process. In 2007, there was a 35.7 percent national compliance rate in the non-Medicare population with the NCQA spirometry recommendation.⁴⁶

This measure showed 1.6 percent decrease from 2006, which indicates the need for additional education on guidelines for the treatment of COPD. Based on NCQA recommendations, California has already implemented the pay-for-performance (P4P) quality improvement program for diabetes and asthma – and the program has potential to significantly improve health care provider practice for COPD.

Another essential feature of quality care for COPD is pulmonary rehabilitation (PR). ATS and ERS define PR as an evidence-based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often experience decreased daily life activities.¹⁶ Comprehensive pulmonary rehabilitation programs include multidisciplinary patient assessment, exercise training, education, and psychosocial support.⁴⁷ Providing individualized treatment for each patient, PR is designed to reduce symptoms, optimize functional status, increase participation in daily activities, and reduce health care costs through stabilizing or reversing systemic manifestations of the disease.⁴⁸ Using PR, the California Collaborative Trial identified benefits that lasted 18 months, including all measures of health care utilization.⁴⁷ The joint American College of Chest Physicians (ACCP)/American Association of Cardiovascular and Pulmonary Research (AACVPR) Evidence-Based Clinical Practice Guidelines outline the evidence-based effectiveness of PR. These include an improvement in dyspnea and health-related quality of life in the short and medium term, improvement of psychosocial indicators, and reduction of health care utilization related to COPD. The guidelines found that longer pulmonary rehabilitation programs produce greater benefits than shorter ones, and that pulmonary rehabilitation is cost-effective.¹⁶

There may be occasional barriers among both healthcare providers and patients when it comes to utilizing pulmonary rehabilitation. Patient barriers include geographic distance from home to the program, transportation, illness and functional status, language, insurance, and cost. Among the providers, there is a clear under-appreciation and suboptimal referral rates to pulmonary rehabilitation which is an essential component in the management of COPD. Pulmonary rehabilitation during and following COPD exacerbation has been found to be safe and effective.

According to the ATS/ERS COPD guidelines, functional status and symptoms should direct the need for referral to PR, not pulmonary function. Patients appropriate for PR have dyspnea or other respiratory symptoms, decreased exercise tolerance, restriction in activities because of their disease or impaired health status.⁴⁷ The GOLD guidelines, on the other hand, recommend referral to pulmonary rehabilitation for patients with FEV₁ of less than 80 percent predicted, GOLD stages II-IV.²⁰

Medicare releases National Coverage Determinations (NCD) when changes are made to medical services/ treatments that were evaluated by the Centers for Medicare and Medicaid Services (CMS) and are now covered by Medicare. Determination of coverage is often related to specific Medicare criteria and guidelines. The establishment of a national coverage determination (NCD) for PR based on inclusion of PR in the Medicare statute in January 2010 holds the potential for improved coverage for PR for Medicare beneficiaries. Strategies are needed to simplify the referral process and improve access to pulmonary rehabilitation programs in California.

Together health plans, medical groups and employers disseminate guidelines and discuss how quality of care for COPD will be measured. Pacific Business Group on Health (PBGH) provides education on targeted disease states to their membership and has created report cards on quality of care at both the health plan and medical group level. They also play a major role in the development of criteria for the California Pay for Performance program.

OBJECTIVE A: Promote the use of the COPD Guidelines.

STRATEGIES

- 1:** Convene COPD stakeholders and experts to adopt and promote existing GOLD and ATS/ERS Guidelines for California. Guidelines focus on early identification of COPD patients, appropriate interventions, and careful monitoring of disease progression with the dual objective of reducing healthcare costs and improving quality and longevity of life for those with COPD. A diverse range of partners will ensure rapid acceptance of any guidelines by practitioners, payors, and patients.
- 2:** Develop and disseminate a COPD Management Toolkit for clinicians to assist in implementing objectives expressed by the GOLD and ATS/ERS Guidelines. The Toolkit should include materials for patients and healthcare providers. Materials for providers should include electronic and blank copies of a COPD Management Plan (see Objective B, page 18) and information on diagnosis and treatment of COPD, managing exacerbations, and spirometry. The Toolkit should also contain educational materials and a list of resources for patients. All materials in the toolkit should be made available online.
- 3:** Increase awareness in the medical community about the importance of providing care consistent with the COPD guidelines by working with large stakeholders representing many healthcare providers. Those stakeholders must agree to promote those guidelines as the standard of care. Identifying “best practice” in the healthcare community will facilitate the adoption of the guidelines.
- 4:** Publicize the COPD guidelines during November each year, which is COPD Awareness Month in California.
- 5:** Investigate/promulgate use of appropriate metrics and pay-for-performance (P4P) models for COPD that would incentivize adherence to the COPD guidelines.

POTENTIAL PARTNERS

The Department of Health and Human Services, National Heart, Lung, and Blood Institute (NHLBI) National COPD campaign, the California Department of Public Health and Department of Health Care Services, Managed Care Division of Medi-Cal, Medicare, the American Lung Association in California, Breathe California, the California Association of Physician Groups (CAPG), state-wide health plans and collaborations for medicine, pharmacy, respiratory therapy, and nursing, the California-focused groups Pacific Business Group on Health (PBGH), the California Quality Collaborative (CQC), the California Thoracic Society, and local medical societies, medical groups, hospital systems, health plans, employer coalitions, and advocacy organizations.

RECOMMENDED PERFORMANCE MEASURES

- Track health care plan/provider compliance with COPD guidelines using COPD-related HEDIS measures.

OBJECTIVE B: Promote the use of written COPD management plans.

STRATEGIES

- 1:** Create or adopt a consensus California COPD Management Plan (CMP). Consider validating existing American Lung Association COPD Management Plan.
- 2:** Consider adding a CMP to the patient-portal of electronic health records.

POTENTIAL PARTNERS

The California Thoracic Society, universities, the California Department of Aging, Kaiser Permanente, Blue Cross/Blue Shield, Brown and Toland, Hill Physicians, and other health systems and insurers.

RECOMMENDED PERFORMANCE MEASURES

- Validation of the American Lung Association in California COPD Management Plan or similar CMP has been conducted.

OBJECTIVE C: Promote pulmonary rehabilitation.

STRATEGIES

- 1: Promote awareness of the potential patient benefits from pulmonary rehabilitation and strategies and systems for referrals to pulmonary rehabilitation. Improve clinician and patient awareness of the GOLD guidelines, evidence-based benefits of pulmonary rehabilitation, and reimbursement may support improved utilization in areas where pulmonary rehabilitation is available.
- 2: Promote processes and tools that make pulmonary rehabilitation referral automatic and reliable for appropriate patients. Samples that could be amended for California already exist.^{49,50} These referral tools should be integrated into electronic medical record systems for ease of use and to prompt providers. Tools should include lists of pulmonary rehabilitation programs in California.^{51,52,53}
- 3: Evaluate outcomes of pulmonary rehabilitation through the creation and maintenance of registries, which serve to pool patient data. Standard evaluation measures should be simple and should be previously validated.
- 4: Address the practical barriers of patients to accessing pulmonary rehabilitation by developing and evaluating novel approaches. Examples include pulmonary rehabilitation on DVD and the Internet.
- 5: Emphasize maintenance of physical activity and other strategies taught during PR on an ongoing basis for all patients with COPD.
- 6: Analyze data from insurers such as Centers for Medicare and Medicaid who can identify % of patients who participates in pulmonary rehabilitation.

POTENTIAL PARTNERS

Professional organizations include the Pulmonary Education and Research Foundation (PERF), American Thoracic Society, American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR), American College of Chest Physicians (ACCP), California Thoracic Society, California Society for Pulmonary Rehabilitation, and the California Society for Respiratory Care. Patient organizations include Emphysema Foundation for Our Right to Survive (EFFORTS), COPD-Alert Support and Advocacy Group, and PERF. Also, pulmonary rehabilitation programs, pharmaceutical companies, oxygen system manufacturers, and durable medical equipment (DME) companies, Centers for Medicare and Medicaid, and insurance companies.

RECOMMENDED PERFORMANCE MEASURES

- Measure number of physicians attending webinar to learn about best practice COPD guidelines and benefits of pulmonary rehabilitation.
- Measure number of health care systems that incorporate referral to pulmonary rehabilitation into their electric records systems.
- Establishment of a patient registry to evaluate outcomes for pulmonary rehabilitation programs.
- Effectiveness of internet and DVD approaches to pulmonary rehabilitation have been evaluated.
- Measure referrals to maintenance programs (Better Breathers Club, gyms, cardiac rehabilitation).

Goal Area 3: Public Health Infrastructure and Advocacy

Goal Statement: Enhance the capacity of the public health system and local advocates to reduce the burden of COPD in California.

Background and Rationale:

Despite being the third-leading cause of death in the United States and the fourth leading cause of death in California, there is little public health infrastructure in place to address COPD. The U.S. Centers for Disease Control and Prevention (CDC) does not have a program to address COPD and does not receive funding from Congress to do so. The California Department of Public Health (CDPH) also lacks resources to establish a formal program to address COPD. COPD continues to be one of the most underfunded diseases compared to costs to society.

| Disease | 2012 NIH Research \$\$ | Deaths Per Disease | \$\$ Per Patient Death | \$\$ Per Patient |
|------------------------|------------------------|--------------------|------------------------|------------------|
| COPD | 120 Million | 141,075 | 851 | 8 |
| Hepatitis C | 102 Million | 12,000 | 8,500 | 23 |
| Cardiovascular Disease | 2.2 Billion | 777,100 | 2,831 | 27 |
| Hepatitis B | 67 Million | 5,000 | 13,400 | 54 |
| Diabetes | 1 Billion | 70,601 | 14,164 | 42 |
| Alzheimer's Disease | 458 Million | 82,476 | 5,553 | 86 |
| Parkinson's Disease | 157 Million | 20,507 | 7,665 | 157 |
| Prostate Cancer | 337 Million | 28,517 | 11,817 | 177 |
| HIV/AIDS | 3.2 Billion | 10,295 | 310,830 | 3,047 |
| Breast Cancer | 778 Million | 41,049 | 18,952 | 3,721 |
| All Cancers Total | 6 Billion | 566,137 | 10,598 | 4,901 |
| West Nile Virus | 46 Million | 45 | 1,022,222 | 46,890 |

* Data from The FAIR Foundation, <http://fairfoundation.org/factslinks.htm>

The Global Strategy for the Diagnosis, Management, and Prevention of Chronic Obstructive Pulmonary Disease outlines guidelines for the management of COPD. These guidelines review how to assess and monitor disease, reduce risk factors, manage stable COPD, and manage exacerbations.²⁰ Unfortunately, not all providers are aware of or follow these guidelines, nor do all insurance plans include coverage for the management components outlined in the guidelines.

COPD is largely preventable and many individuals diagnosed with COPD are passionate about preventing others from developing the disease. Armed with advocacy training and working with groups that have similar interests, these motivated patients could advance the importance of preventing COPD by advocating for additional resources to be devoted to addressing COPD in California.

In many other chronic diseases, including asthma, community coalitions have played a major role in increasing awareness and understanding of the disease among patients, health care providers, and the general public. As coordinated networks of individuals who represent different interests but share a common goal, COPD coalitions could have a greater impact than individuals or organizations working on their own. The California COPD Coalition is comprised of several committed organizations and individuals, but expanding its membership would increase representation from all sectors of COPD stakeholders and improve sustainability. Coordination of local COPD coalitions into a network of coalitions led by the state COPD coalition would ensure that coalitions can learn from each other's successes and challenges and combine their efforts and resources to achieve the overarching goal of reducing the burden of COPD in California.

OBJECTIVE A: Support the development, funding, and staffing of a state public health program focused on COPD.

STRATEGIES

- 1:** Support the development and passage of legislation directing the California Department of Public Health (CDPH) to establish and allocate sufficient funding for a program aimed at reducing the burden of COPD in California. Potential activities of a CDPH COPD program would include raising awareness of COPD as a significant public health issue, COPD surveillance, promotion of guidelines-based COPD care, and prevention of COPD through tobacco control efforts, workplace protections, and reduced exposure to air pollution (particulate matter).
- 2:** Assist the California Department of Public Health in identifying and recruiting high-caliber program staff to address COPD in California.
- 3:** Ensure the CDPH COPD program coordinates its program activities with efforts conducted by the California COPD Coalition and other stakeholders.

POTENTIAL PARTNERS

Emphysema Foundation For Our Right to Survive (EFFORTS), Alpha-1 Foundation, the COPD Foundation, the American Lung Association in California, California Assembly or Senate members, and the California Thoracic Society.

RECOMMENDED PERFORMANCE MEASURES

- Advocacy plan to support passage of legislation which includes identifying and contacting key decision makers (CDPH leadership, elected officials, COPD champions) is developed with defined timeline.

OBJECTIVE B: Build the capacity of the California COPD Coalition

STRATEGIES

- 1:** Recruit stakeholders representing all sectors of COPD prevention and control to join the California COPD Coalition and actively participate in coalition activities.

POTENTIAL PARTNERS

The American Lung Association in California, California Thoracic Society, the California Department of Public Health, and pharmaceutical companies.

RECOMMENDED PERFORMANCE MEASURES

- All sectors have been identified and a comprehensive list of potential stakeholders developed.
- Recruitment strategy is developed and potential role for members is defined.

OBJECTIVE C: Develop and support a network of local community partner coalitions to increase awareness and understanding of COPD among patients, health care providers, local policy-makers, and the general public.

STRATEGIES

- 1: Assist COPD stakeholders to form local COPD coalitions.
- 2: Provide support and technical assistance for the activities of local COPD coalitions by establishing a statewide network of local COPD coalitions coordinated by the California COPD Coalition.

POTENTIAL PARTNERS

The American Lung Association in California, pharmaceutical companies, health care providers, insurers, employers, industry, local Better Breathers clubs, local COPD coalitions, and possibly some asthma coalitions.

RECOMMENDED PERFORMANCE MEASURES

- Identify existing asthma coalitions or other lung health coalitions that might consider expanding to include COPD as a focus.

OBJECTIVE D: Enhance the capacity of patients and patient groups to advocate for health care that is consistent with COPD management guidelines.

STRATEGIES

- 1: Provide local COPD patient groups or local COPD coalitions with copies of the GOLD guidelines for dissemination to health care providers and insurers.
- 2: Develop and disseminate patient education materials that outline the components of guideline-based COPD management in order to raise patient expectations for quality COPD care.
- 3: Train local patient groups or local COPD coalitions to advocate for improved health care for individuals with COPD, including the receipt of guideline-based COPD management and comprehensive insurance coverage of guideline-based care.

POTENTIAL PARTNERS

The American Lung Association in California, the California Thoracic Society, local Better Breathers clubs, and local COPD coalitions.

RECOMMENDED PERFORMANCE MEASURES

- Measure number of COPD guidelines distributed to health care providers and insurers.

OBJECTIVE E: Enhance the capacity of COPD patients and patient groups to advocate for increased investment in COPD prevention.

STRATEGIES

- 1:** Provide ongoing training and technical assistance to local patient groups and local COPD coalitions about major causes of COPD. These causes include exposure to tobacco smoke, indoor and outdoor particulate matter pollution, and occupational exposures to vapors, gases, dusts, and fumes.
- 2:** Encourage local patient groups or local COPD coalitions to collaborate with groups and coalitions that have shared interests in optimizing respiratory health, such as asthma, tobacco, and clean air coalitions, to advocate for clean air indoors, outdoors, and at work.

POTENTIAL PARTNERS

The American Lung Association in California, the California Department of Public Health, California's Clean Air Project, California Air Resources Board, and Center for Tobacco Policy and Organizing. Locally, Better Breather clubs, tobacco coalitions, asthma coalitions, air quality coalitions, and COPD coalitions.

RECOMMENDED PERFORMANCE MEASURES

- Local, statewide or nationwide COPD organizations that can provide training are identified.
- Asthma coalitions will be approached to include COPD in their focus areas.

Goal Area 4: Surveillance

Goal Statement: Assess the scope of COPD in California through the creation of a statewide surveillance system.

Background and Rationale:

Public health surveillance is the ongoing systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action.⁵⁴ In the case of COPD, ongoing surveillance is necessary to determine how many Californians have COPD (prevalence), how many Californians have reduced quality of life due to COPD (morbidity), and how many Californians die from COPD (mortality). Surveillance allows us to detect trends in COPD-related prevalence, morbidity, and mortality, and to evaluate our collective efforts to minimize the burden of COPD. Surveillance provides data that serve as the basis for educating policy makers, analyzing the impact of policy decisions, projecting future costs to state and local governments and health plans, directing government and private resources, enhancing proposals to potential funders, and educating the public, especially through mass media.

Chronic disease surveillance typically measures the following types of data:

- Incidence (new cases of disease per year)
- Prevalence
- Mortality
- Hospitalizations
- Emergency department or urgent care utilization
- Disease severity
- Quality of life
- Medication use
- Risk factors for disease development or exacerbation
- Health disparities, using any of the above indicators

Up until 2012, there has been little data on COPD available in California. Due to the high cost of collecting original data, previous state surveillance efforts have focused on existing data sources, such as surveys and health care utilization records. Current estimates of lifetime COPD prevalence in California are calculated by applying age-specific national prevalence rates from the National Health Interview Survey (NHIS) to the California population. No survey has included a large enough sample of California residents to allow for a direct assessment of California's COPD prevalence.

The California Health Interview Survey (CHIS), a biennial telephone survey of over 50,000 Californians, previously attempted to capture the prevalence of non-asthma lung diseases. The results are of limited use in determining the prevalence of COPD in California because the questions lacked sensitivity or specificity. In 2003, the survey asked those without asthma, "During the past 12 months, have you ever had a wheezing or whistling sound in your chest?" and noted those who mentioned bronchitis, emphysema, or COPD.⁵⁵ In 2005, the survey asked, "Has a doctor ever told you that you have a lung disease other than asthma, such as emphysema or COPD?"⁵⁶ Although CHIS has tremendous potential for COPD surveillance, the cost of adding questions to this survey to obtain data specific to COPD may be prohibitive.

The Behavioral Risk Factor Surveillance System (BRFSS) is a national telephone survey administered by the U.S. Centers for Disease Control and Prevention (CDC) annually. Statistics can be produced from BRFSS at the state level and for some larger municipal areas. Thanks to advocacy by the American Lung Association and other COPD organizations, the CDC has included the following question in the BRFSS core module beginning in 2012. "Have you ever been told by a doctor or health professional that you have chronic obstructive pulmonary disease (COPD), emphysema or chronic bronchitis?"

This is the first time a COPD question has been included on the BRFSS survey and will provide important COPD prevalence data for California.

Several additional COPD questions were included in the optional module developed by North Carolina:

- Have you ever been given breathing test to diagnose your COPD, chronic bronchitis, or emphysema?
- Would you say that shortness of breath affects the quality of your life?
- Other than a routine visit, have you had to see a doctor in the past 12 months for symptoms related to shortness of breath, bronchitis, or other COPD or emphysema flare?
- Did you have to visit an emergency room or be admitted to the hospital in the past 12 months because of your COPD, chronic bronchitis, or emphysema?
- How many different medications do you currently take each day to help with your COPD, chronic bronchitis, or emphysema?

California is among 20 states that have added customized COPD-related questions to their state's BRFSS, at their own expense. These questions will provide additional data about COPD related health care utilization, quality of life, emergency room use and medication utilization.

It is recognized that COPD is under-reported—as many as half of people with COPD do not know they have it.³ A more accurate estimate of COPD prevalence requires additional symptom-based questions to get at probable undiagnosed COPD. To this end, a validated five-question COPD screening tool with 84 percent sensitivity has been developed.⁵⁷ This tool could be adapted for use on BRFSS or other surveys.

In California, data that could be used to calculate COPD-related mortality, hospitalization, and emergency department visit rates are already collected. The California Department of Public Health (CDPH) collects data on all deaths, while the Office of Statewide Health Planning and Development (OSHPD) collects data on all hospitalizations and emergency department visits. CDPH and OSHPD data are available at no cost to analysts within CDPH and local health departments, and for a small fee to other researchers. Since the data are available as individual records, a skilled end-user familiar with statistical programming is needed to analyze the data. CDPH and OSHPD could be ongoing sources of data on COPD-related mortality, hospitalizations, and emergency department encounters.

Mortality and morbidity data for COPD are confounded by the fact that there are often co-morbid conditions that contribute to COPD mortality and morbidity, such as heart disease and other respiratory conditions. Because BRFSS collects data on several health conditions, it can serve as a source of COPD co-morbidity data. Other sources of co-morbidity data, including proprietary sources, should also be explored.

The National Committee for Quality Assurance (NCQA) has developed the Healthcare Effectiveness Data and Information Set (HEDIS) to measure performance on important dimensions of care and service. Over 90 percent of health plans in the United States use HEDIS, making it an excellent source of data on quality of care. There are currently two COPD-related HEDIS measures: 1) Use of spirometry testing in the assessment and diagnosis of COPD and 2) Pharmacotherapy of COPD exacerbation.⁵⁸

OBJECTIVE A: Establish infrastructure for the collection and analysis of COPD data in California.

STRATEGIES

- 1:** Allocate state funding to analyze COPD-related questions to the California BRFSS questionnaire in order to obtain ongoing assessment of COPD prevalence in California. The questions should also assess acute COPD-related health events.
- 2:** Allocate state funding and resources to regularly advocate for the inclusion of a COPD-related question on the national BRFSS core questionnaire, and obtain such data when it becomes available. Ensure that the questions for Strategy 1 above complement, not duplicate, the information that would be gathered by the national BRFSS.
- 3:** Regularly obtain and analyze COPD-related hospitalization, emergency department utilization, and mortality data from the California Department of Public Health and the Office of Statewide Health Planning and Development.
- 4:** Track health care plan/provider compliance with COPD guidelines using COPD-related HEDIS measures.
- 5:** Explore the feasibility of obtaining and analyzing additional indicators for COPD surveillance. Suggested topics include COPD severity, quality of life, co-morbidities, medications, and oxygen use. Potential data sources for COPD severity and quality of life are BRFSS and CHIS. BRFSS, OSHPD, Medi-Cal, and Kaiser Permanente can provide data on COPD co-morbidities. Medi-Cal Fee-for-Service, Kaiser Permanente, private health plans, and durable medical equipment providers can provide data for medication and oxygen use.

POTENTIAL PARTNERS

The National Committee for Quality Assurance (NCQA), national Centers for Medicare and Medicaid Services, the California Department of Public Health's Chronic Disease Control and Environmental Health Investigations Branches, California Department of Health Care Services, Office of Statewide Health Planning and Development, Survey Research Group, Kaiser Permanente, private health plans, and durable medical equipment providers.

RECOMMENDED PERFORMANCE MEASURES

- Collect and disseminate COPD prevalence data from the California BRFSS questionnaire.
- De-identified data on COPD-related hospitalizations for at least most recent 5 years obtained from OSHPD; de-identified data on COPD-related emergency department visits since 2005 obtained from OSHPD; and de-identified data on COPD-related deaths for at least most recent five years obtained from California Department of Public Health.
- Obtain at least state-level data for the two COPD-related HEDIS measures from NCQA.
- Data for at least one additional COPD-related indicator obtained and analyzed.

OBJECTIVE B: Disseminate COPD-related data to stakeholders throughout California.

STRATEGIES

- 1:** Create the first California COPD Surveillance Report based on the data obtained and analyzed above. The report should include relevant aggregate statistics for the state and, when possible, for county and metropolitan areas as well as socio-geo-demographic groups. The report should contain easy-to-understand graphs to illustrate the burden of COPD in California, including COPD prevalence, mortality, hospitalizations, emergency department visits, and quality of care measures. The report should also document trends over time, establishing baselines where needed, and should report statistics by socio-geo-demographic groups to determine disparities. “The Burden of Asthma in California: A Surveillance Report” can serve as a template.⁵⁹
- 2:** Disseminate the California COPD Surveillance Report to all stakeholders, including COPD Coalition members, state and local public health departments, pulmonary rehabilitation programs, COPD researchers, tobacco coalitions, managed care organizations, pharmaceutical companies, and California Thoracic Society members.
- 3:** Update the COPD Surveillance Report every 5-10 years, adding new data sources as they become available.
- 4:** Conduct and publish descriptive epidemiological studies using surveillance data. Once data sources are identified, it will be possible to conduct cross-sectional and possibly longitudinal epidemiological studies to learn more about COPD in California.

POTENTIAL PARTNERS

The California Department of Public Health’s Environmental Health Investigations and Chronic Disease Control Branches, the American Lung Association in California.

RECOMMENDED PERFORMANCE MEASURES

- At least one epidemiologic study using California COPD surveillance data published in a peer-reviewed journal.

Goal Area 5: Research

Goal Statement: Leverage California's unique resources to maximize research into COPD prevention, diagnosis and treatment.

Without a seminal discovery and rapid development of a highly effective new therapy, COPD will remain a leading cause of death worldwide, behind only heart disease and cancer.⁶⁰ The National Lung Health Education Project has pointed to the major reduction in premature morbidity and mortality from heart attack and stroke as one of the greatest public health success stories in this country.⁶¹ This reduction was accomplished due to massive research and public education and funding by several governmental organizations, including the National Institutes of Health. Confidently, we can predict that the spiraling incidences of death and disability due to COPD will be forestalled if public and private health and research organizations invest in research and public education programs, similar in scope to those used to impact heart disease, stroke, and AIDS. California is well positioned to be a leader in this effort.

Unique California Resources

California's reputation as a leader in health care excellence, both regionally and nationally, combined with its world class universities and medical centers, creates an ideal climate for COPD research. The states burgeoning biotechnology and stem cell research industries offer unique opportunities for collaboration in ground-breaking research that can lead to significant improvements in the care and treatment of patients with COPD. Additionally, California's environmental attributes offer promising opportunities for research. The state is home to the highest levels of air pollution in the country,⁶² but is among the lowest smoking rates.⁶³ The state also boasts a diverse population with a broad array of insurance models and varying access to critical health care that are important factors in disease management and treatment. And finally, an openness to collaboration among clinicians, patients, and researchers and a readiness to explore complementary therapies such as yoga are other key components of California's research climate.

Creating a strong research program will require both funding and a commitment to building the infrastructure that can facilitate collaboration among the many entities in California. The American Lung Association in California can lead these efforts by building on its existing research program that supports basic and clinical research through training and "seed" grants for beginning researchers, which play a critical role in attracting and retaining talented scientists who are focused on lung research. While the scope of the funding may be broad (basic through applied), the intent should be to provide small seed grants making possible the generation of preliminary original data supporting follow-on applications for more substantial sustained funding [e.g., federal centers, individual National Institutes of Health (NIH), ROI or K99/RO0, Department of Veterans Affairs (VA), or National Science Foundation (NSF) grant support]. Important too will be developing a system to disseminate and communicate critical research findings to the health and medical community.

Background and Rationale:

The economic effect of COPD – especially on acute medical care – has been well documented, with more than \$42.6 billion spent on COPD in the U.S. in 2007.⁵ COPD has not received the attention it deserves. Compared with other major killers, such as cardiovascular disease and stroke, COPD is under-diagnosed, under-treated, under-funded, and neglected by the public, pharmaceutical industry, and granting agencies.⁶⁴ This neglect is sadly due in part to the misperception that COPD is a self-inflicted smokers' disease that affects only elderly people and has no effective treatment. COPD continues to be one of the most underfunded diseases in terms of research dollars.

A working group convened in 2002 by the National Heart, Lung, and Blood Institute entitled "Clinical Research in COPD: Needs and Opportunities," identified several recommendations for research that could apply to California. Those include the establishment of a multicenter Clinical Research Network to perform multiple, short-term clinical trials of treatments in patients with moderate-to-severe COPD and creating a system for the standardized collection, processing, and distribution of lung tissue specimens and associated clinical and laboratory data. The strategies included in this report are designed to lay a foundation for building an effective network of clinical research and data collection.⁶⁵

Current COPD research is largely focused on classifying sub-populations of the illness,^{66,67} impacts of long-term oxygen therapy,⁶⁸ self management of the illness,^{69,70} and on newer generations of pharmaceutical agents originally developed for asthma.⁷¹ Little research has been done on risk factors beyond smoking, and there is no drug to stop progression of the disease.⁷² COPD lags behind other chronic illnesses in answering basic research questions such as a) medications tailored to the specific pathophysiology of the disease, b) advanced diagnostic techniques that detect sub-clinical disease before symptoms are evident, c) effective patient-centered and complementary therapies, d) systemic manifestations of the disease, and e) biological mechanisms, including genetics, inflammatory processes and the environment.

There is a significant need for more basic, translational and clinical research into the etiology and management of COPD.⁶⁵ Basic research includes novel, fundamental discoveries which are essential to fuel the pipeline of potential new therapies that will ultimately improve the management of those suffering with COPD. Translational research is applied research aimed at the translation to human disease of fundamental observations, often reported from California's many strong academic centers. In clinical research, basic and translational research is implemented and tested in real world clinical settings. Both basic and applied research of COPD should be multidisciplinary when possible, involving collaborations of MD and PhD lung researchers with engineers, respiratory therapists, nurses, and social workers, among others.

Selected promising new pharmaceutical approaches meriting further research investment include modifying the immune and inflammatory processes unique to COPD, strengthening the antioxidant capabilities of the lung, improving alveolar plasticity, and decreasing production of mucus through regulation of goblet and glandular mucus cells. Biospecimens collected from COPD subjects can support research of these new pharmaceutical approaches. Examples include sera, plasma, peripheral blood mononuclear cells, induced sputa, exhaled breath condensates, bronchoalveolar lavage fluids, and lung biopsy specimens of all types including surgical specimens. Such biospecimens are essential for research hoping to translate fundamental or animal model observations to humans and are applied in research settings to identify biomarkers of disease activity or potential response to therapy.⁷³

While the tools needed to quantify inflammatory cells, gene expression, protein content, and cellular phenotype are currently available, the development of new medications, as well as illumination of mechanisms of disease initiation and progression proceeding over decades, would be facilitated by more sensitive diagnostic techniques.⁷⁴ Improvements in lung imaging are needed to detect sub-clinical disease before symptoms become prominent in order to identify targets for effective interventions. Traditional diagnostic tools may not reveal subtle differences in COPD disease that can have important prognostic or therapeutic implications.

Research in California can benefit from a patient population that is receptive to alternative and complementary approaches to disease and symptom management, such as exercise, breathing strategies and technology-enhanced patient support.⁷⁵ The American Lung Association network of Better Breathers Clubs is a rich source of patient-generated management strategies for improving quality of life and decreasing symptom burden relating to the disease. Support groups and engaged COPD patients are an untapped resource to test the efficacy of complementary strategies to improve disease management.

The systemic manifestations and common comorbidities of COPD have recently become a focus of research. It is not widely recognized by physicians that COPD should no longer be judged as simply a lung disease. COPD includes systemic manifestations such as muscle wasting, metabolic changes and depression.⁷⁶ Co-morbidities such as cardiovascular disease share some risk factors with COPD like cigarette smoking and chronic inflammation which may explain why these conditions often occur together. It has been proposed that the term "chronic systemic inflammatory syndrome" be added as a characteristic of COPD to stimulate discussion of the frequent complex chronic co-morbidities that often accompany this disease.⁷⁷

Studies exploring the genetic variation in COPD subtypes or differences in symptom experience could ultimately lead to personalized medicine for COPD. Knowledge of the impact of a wide variety of environmental factors (toxic exposures, diet, physical activity, and sleep deprivation) is necessary for a better understanding of COPD. Determining the mechanisms by which such factors disrupt normal biology and interact with genetic susceptibility should be an important objective of future research.

California's rich pool of researchers, physicians, academic institutions, biotechnology and pharmaceutical industry as well as patients, offers a promising environment for advances in basic, translational and clinical COPD research. With COPD now the third leading cause of death in the United States, California can draw from a broad group of stakeholders who stand ready to dedicate their energies to decrease morbidity and mortality and improve quality of life for patients with COPD. Given the pace of scientific discoveries, it is essential that California remain vigilant and nimble in identifying and embracing critical research opportunities as they arise.

OBJECTIVE A: Augment California's research infrastructure.

STRATEGIES

- 1:** Leveraging the world-class institutions and industry clustered in California, convene a roundtable of public and private institutions with the intent of generating a powerful consortium focused on COPD research.
- 2:** Create a statewide database of pulmonary clinics and rehabilitation centers wishing to collaborate on COPD studies.
- 3:** Create a statewide registry of patients who wish to participate in clinical trials.
- 4:** Create a database of archived biospecimen
- 5:** Collaborate with CTS to identify expert researchers willing to mentor clinicians who have interest in developing COPD research projects.
- 6:** Fund seed grants addressing COPD through state and national research programs of the American Lung Association.

POTENTIAL PARTNERS

California Thoracic Society (CTS), academic medical centers in California, California Society of Pulmonary Rehabilitation (CSPR) and pulmonary rehabilitation facilities, Better Breathers Clubs, pulmonary clinics and physician offices, California Institute for Regenerative Medicine, biotechnology and pharmaceutical companies, and complementary health centers.

RECOMMENDED PERFORMANCE MEASURES

- Potential organizations identified that have resources to develop database of clinics and rehabilitation centers.
- Identify existing models for patient registries that meet HIPAA restrictions.
- Identify academic and research organizations that are conducting research utilizing biospecimens.
- Campaign by the American Lung Association in California to raise money for research seed grants in California is conducted.

OBJECTIVE B: Organize and disseminate the latest research findings.

STRATEGIES

- 1:** Track the impact that research seed funds have had on generating additional research funding as well as publication of peer-reviewed articles and adoption in best practice guidelines.
- 2:** Monitor COPD section of Up to Date and ATS Year in Review on COPD (annually in May), summarize for yearly CTS Inspirations newsletter and disseminate.
- 3:** Hire development director dedicated to securing unrestricted grant funding from industry, foundations, government and individuals to support American Lung Association in California research program.
- 4:** Convene ALA in CA-funded researchers annually to share updates and provide summary of progress. Disseminate abstracts and progress reports in annual ALA in CA research report.

POTENTIAL PARTNERS

COPD Strategic Plan stakeholders list, industry, foundations, government, elected officials, M.D. and Ph.D. lung researchers, engineers, respiratory therapists, nurses, and social workers, among others.

Goal Area 6: Public Education and Awareness

Goal Statement: Increase public awareness and understanding of COPD.

Background and Rationale:

In a 2008 nationwide survey of 8,200 adults, only 64 percent of respondents had ever heard of COPD. Among those who reported hearing of COPD, only half recognized the disease as a leading cause of death, just 44 percent understood it to be treatable, and only five percent recognized chronic cough as a symptom of the disease. Remarkably, only 22 percent of *smokers* who took the survey recognized that their smoking puts them at greater risk for COPD.⁷⁸

Given that COPD is the third-leading cause of death in the United States, the only one that is increasing out of the top 10, and one of the top causes of healthcare expenses⁷⁹, it is astounding how little the general public knows about COPD. It is quite likely that the public is confused about the term “COPD” as its constituent conditions – emphysema and chronic bronchitis – appear to be more recognizable by the public. In any case, the lack of public awareness has several implications:

- Individuals who smoke are less likely to be aware that the smoking can lead to COPD.
- Individuals with undiagnosed COPD will be less likely to seek early medical intervention, or to get a diagnosis early in the disease’s progression. In 2009, 13.1 million U.S. adults (aged 18 and over) were estimated to have COPD.⁸⁰ However, close to 24 million U.S. adults have evidence of impaired lung function, indicating an under-diagnosis of COPD.¹¹
- Without a public that really understands what COPD is, it is unlikely that adequate pressure will be placed on public officials to implement appropriate policies, such as financing of pulmonary rehabilitation, or to invest more in COPD-related research. In 2008, COPD ranked 130th out of all diseases entities in research funding from the National Institutes for Health.⁸¹
- Once diagnosed, individuals will be less likely to advocate for appropriate treatment and to know how to live life to the fullest.

COPD patients who cannot access a pulmonary rehabilitation program often have insufficient information about the condition to maximize their quality of life. Limited time is available with medical providers for a comprehensive review of what a patient needs to know. Many patients are unable to proactively access the available resources online.

In the 1990s, the National Lung Health Education Program, an initiative of the National Heart, Lung, and Blood Institute, launched a “Test Your Lungs/Know Your Numbers” campaign to encourage all smokers and any patient with cough, mucus, wheeze or dyspnea to have spirometric tests done by their primary care physician to help diagnose COPD among those who may not know they have it. The campaign has since been supported by the American Association for Respiratory Care and the COPD Foundation and could serve as the basis for a campaign for the Strategic Plan to Address COPD in California.

To improve awareness among the public, smokers, and COPD patients, the National Heart, Lung, and Blood Institute (NHLBI) launched the *COPD: Learn More Breathe Better*[®] campaign in 2007 to increase awareness and understanding of COPD and its risk factors, and to underscore the benefits of early detection and treatment in slowing the disease and improving quality of life. The campaign, supported by more than 20 organizations including the American Lung Association, has public service announcements (PSAs), b-roll footage, handouts, and posters available free to the public on the NHLBI website.⁷⁷

To raise awareness of COPD in California, Assembly Concurrent Resolution (ACR) 62 (the Galgiani Resolution) has declared November as COPD Awareness month and encourages the state Department of Health Care Services, the State Department of Public Health and other state entities to partner with chronic obstructive pulmonary disease (COPD) stakeholders to improve education regarding COPD in the course of implementing the statewide strategic plan. The resolution also encourages public officials and the citizens of California to increase awareness of the symptoms of, and the methods of preventing COPD.

OBJECTIVE A: Utilize mass media opportunities to increase the general public’s awareness of chronic lung disease, particularly the term COPD, its cost to families and taxpayers, and its risk factors.

STRATEGIES

- 1: Disseminate *Strategic Plan to Address COPD in California* in conjunction with November COPD Awareness Month.
- 2: Conduct webinars for health professionals and organizations on *Strategic Plan to Address COPD in California*.
- 3: Disseminate the National Heart, Lung, and Blood Institute’s COPD: Learn More Breathe Better® campaign materials to media throughout California, including print and radio PSAs and campaign fact sheets for at-risk and diagnosed patients.
- 4: Explore Web 2.0 strategies to share information, including social networking platforms such as Facebook and Twitter, targeting people with COPD and caregivers.

POTENTIAL PARTNERS

The American Lung Association in California, California Department of Public Health, the California Thoracic Society, local COPD researchers, local Better Breather Clubs, hospital respiratory therapy departments, medical providers, and pulmonary rehabilitation programs.

RECOMMENDED PERFORMANCE MEASURES

- Media campaign developed and conducted to highlight updated COPD plan in conjunction with COPD awareness month.
- Webinar will be conducted annually as part of COPD awareness month.

OBJECTIVE B: Collaborate with the tobacco control community to increase public awareness of COPD and educate smokers about the disease.

STRATEGIES

- 1: COPD stakeholders should work with the tobacco control community to ensure they are educated about COPD and are willing and able to talk about COPD during media opportunities. The tobacco control community in California is very experienced in working with mass media to educate the public about the dangers of tobacco smoke and furthering tobacco control policies. COPD is the most common serious condition associated with tobacco use and exposure.
- 2: Provide training and materials to the California Smokers’ Helpline to enable the Helpline staff to educate callers about COPD.
- 3: Provide training on COPD for front line cessation specialists in the local community, enabling them to educate quitters on COPD risks.
- 4: Provide posters about COPD and smoking cessation to employers to post in employee work rooms.

POTENTIAL PARTNERS

The American Lung Association in California’s Center for Tobacco Policy and Organizing, California Department of Public Health, The Center for Tobacco Cessation (University of California San Diego), and state and local Tobacco Control staff.

RECOMMENDED PERFORMANCE MEASURES

- Tobacco coalitions will include increased awareness of COPD in their strategic plans.

OBJECTIVE C: Improve patient understanding about COPD management and prevention.

STRATEGIES

- 1: Work with COPD partner organizations to promote a *Know Your Numbers* campaign to raise awareness on the importance of pulmonary function tests,.
- 2: Disseminate an educational DVD for patients with COPD available through the American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR).
- 3: Create a COPD self-assessment tool to assess level of control, similar to the Asthma Control Test.
- 4: Increase awareness of existing online resources (e.g., COPD Foundation, American Lung Association, Emphysema Foundation for Our Right to Survive [EFFORTS] COPD-Alert) and in-person support groups such as Better Breathers Clubs, by adding links to existing websites that are affiliated with members of the California COPD Coalition, and including information in newsletters such as those put out by health plans and hospitals.
- 5: Promote the use of the American Lung Association's Lung Helpline, which provides free support, advice, and materials for callers. The Lung Helpline is staffed by medical professionals and has multi-language capacity. This resource can be promoted via existing websites and newsletters.
- 6: Promote the American Lung Association in California Respiratory Rallies, one-day patient educational workshops providing education and raising awareness about COPD.
- 7: Develop a speakers bureau, and create a standardized slide set for use by health care professionals (RN, RRTs, etc.) to educate the community about COPD.
- 8: Promote prevention and management through Pulmonary Rehabilitation newsletters, including those from Seton Hospital, Sequoia Hospital, Mission Viejo Hospital and national newsletters such as *Everything Respiratory*, the COPD Foundation newsletter, and *The Pulmonary Paper*.
- 9: Collaborate with organizations that target seniors, such as the AARP.

POTENTIAL PARTNERS

The COPD Foundation, California Thoracic Society, AARP, American Lung Association in California, California COPD Coalition members, the California Department of Aging, and local senior settings such as adult day health programs and area agencies on aging.

RECOMMENDED PERFORMANCE MEASURES

- Increased number of calls to Lung HelpLine related to COPD.

OBJECTIVE D: Improve awareness of COPD among policy-makers.

STRATEGIES

- 1: Develop a list of professional speakers to represent the California COPD Coalition who can be utilized as needed to educate elected officials about COPD and specific policies that may affect Californians with COPD.
- 2: Educate California members of the Congressional COPD Caucus (Susan Davis, Dianne Feinstein, Bob Filner, and Zoe Lofgren) about the California COPD Coalition and the *Strategic Plan to Address COPD in California*.
- 3: Utilize the National Health, Lung, and Blood Institute's *COPD Learn More Breathe Better*[®] materials as simple primers about COPD to be used with policy-makers.

POTENTIAL PARTNERS

California COPD Coalition Members, National Health, Lung, and Blood Institute's *COPD Learn More Breathe Better*[®] campaign, and California members of COPD Caucus.

RECOMMENDED PERFORMANCE MEASURES

- Medical experts, COPD patient advocates, and COPD champions are identified.
- Individual visits are made to COPD caucus members by COPD Coalition members.

Appendix A: COPD Resources

General Resources

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| Global Initiative for Chronic Obstructive Lung Disease (GOLD) | Aims to increase awareness of COPD and improve its prevention and treatment worldwide by developing guidelines for COPD management and hosting events such as World COPD Day. | www.goldcopd.com |
| International COPD Coalition | Coalition of international public interest organization and lay advocacy groups. | www.internationalcopd.org |
| Pulmonary Rehabilitation Programs in California | Provides updated list of pulmonary rehab programs throughout California with contact information. | www.lung.org/california-copd www.cspr.org |

Support Groups and Coalitions

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| Better Breathers Clubs | Local COPD support groups typically run by volunteers with support from the American Lung Association. There are about 40 of these groups throughout California. | www.lung.org/california-copd |
| COPD-Alert.com | Support and advocacy group for COPD patients, caregivers, medical professionals, and others; provides information on COPD-related activities in the U.S., including clinical trials and conferences. | www.COPD-Alert.com |
| COPD Council | Comprised of leaders of support of all levels, provides a forum for the leadership of COPD support groups to work together for the benefit of the patient. Includes a directory of support groups, an event calendar, and listings of speakers. | www.COPDCouncil.org |
| COPD-International | Information and interactive support for COPD patients, caregivers, families, and interested individuals; features chat rooms, message boards, e-mail lists, quit smoking and exercise support, a contact program for those living alone, an extensive library, Bill Horden's COPD-Advocate, the COPD Survival Guide, and a weekly internet newsletter | www.COPD-International.com |
| COPD-Support | The web home for the chronic obstructive pulmonary Disease (COPD) online mailing list including COPD support and COPD caregiver services, chat rooms, message board, a newsletter, exercise support, and quit smoking support. | www.COPD-Support.com |
| EFFORTS (Emphysema Foundation for Our Right to Survive) | An online support group (> 2,500 members) dedicated to furthering research efforts, public education, government education, and helping those with COPD cope with the disease by sharing various resources. | www.emphysema.net |

State Organizations

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| <p>American Lung Association in California (ALA in CA)</p> | <p>The American Lung Association in California saves lives and improves the health of Californians and their lungs. Through research, education and advocacy, the organization fights to reduce smoking, keep the air clean, prevent and treat lung diseases such as asthma and COPD, and eliminate lung cancer.</p> | <p>http://www.lung.org/california</p> |
| <p>California Society for Pulmonary Rehabilitation (CSPR)</p> | <p>Founded in 1986, CSPR is comprised of Physicians, Respiratory Care Practitioners, Registered Nurses, Exercise Physiologists, Physical Therapists, Occupational Therapists, as well as other health care professionals.</p> <p>The CSPR is dedicated to providing professional education and communication for the advancement of pulmonary health and rehabilitation.</p> | <p>http://www.cspr.org</p> |
| <p>California Thoracic Society (CTS)</p> | <p>CTS is a chapter member of the American Thoracic Society whose mission is to improve health in California by advancing research, clinical care, and public health in respiratory disease, critical illness and sleep disorders.</p> | <p>http://www.calthoracic.org/</p> |
| <p>California Society for Respiratory Care (CSRC)</p> | <p>An affiliate of the American Association of Respiratory Care (AARC), CSRC is a non-profit professional organization, whose mission is to represent and support its members through public and legislative advocacy, educational opportunities, and to continuously strive for excellence in the cardiopulmonary profession. By these means, the CSRC is committed to health, healing and disease prevention in the California community.</p> | <p>http://www.csrc.org/</p> |

National Organizations

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| Alpha-1 Foundation | Dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1. | www.alphaone.org (877) 228-7321 |
| American Association of Respiratory Care (AARC) | Supports respiratory therapists who provide respiratory care and training. | www.aarc.org (972) 243-2272 |
| American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR) | Through education, prevention, rehabilitation, research and disease management, this multidisciplinary professional association, comprised of approximately 3000 health professionals, works to improve the quality of life for patients and their families by reducing morbidity, mortality and disability from cardiovascular and pulmonary disease. They also host the Directory of Rehabilitation Programs that include nationally certified programs. | www.aacvpr.org (312) 321-5146 |
| American College of Chest Physicians | Over 15,000 physicians dedicated to research, teaching, and cardiopulmonary medicine, surgery and critical care. | www.chestnet.org (847) 498-1400 |
| American Lung Association (ALA) | Through research, education, community service, and advocacy, the ALA works to prevent lung disease and promote lung health. ALA coordinates COPD support groups, provides educational materials and seminars for COPD patients and people interested in quitting tobacco, and sponsors COPD related research. | www.lung.org (800) LUNG-USA |
| American Sleep Apnea Association | An extensive resource of information on sleep apnea, publications, information packets, and an extensive list of related links in the U.S. and other countries. | www.sleepapnea.org (202) 293-3650 |
| American Thoracic Society (ATS) | ATS is an independently incorporated, international educational and scientific society which focuses on respiratory and critical care medicine. Members help prevent and fight respiratory disease around the globe through research, education, patient care, and advocacy. The long-range goal is to decrease morbidity and mortality from respiratory disorders. | www.thoracic.org (212) 315-8600 |
| COPD Foundation | The COPD Foundation grew out of the recognized need to advance research, patient care, and patient and professional education in COPD. Another purpose of the Foundation is to increase public and professional awareness of COPD. | www.copdfoundation.org (888) 825-7421 |
| International COPD Coalition | International public interest organization and lay advocacy groups. | www.internationalcopd.org |
| National Council on the Aging (NCOA) | Benefits CheckUp, a program of NCOA, helps thousands every day to find programs for people ages 55 and over that may pay for some costs of prescription drugs, health care, utilities, and other essential items or services. | www.benefitscheckup.org (202) 479-1200 |

National Organizations

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| National Emphysema Foundation | Works to improve the quality of life for those with emphysema, asthma, and related diseases through education, research, and patient care. | http://emphysemafoundation.org (203) 854-9191 |
| The National Emphysema/COPD Association (NECA) | Dedicated to providing support and information to people suffering from COPD, including what COPD is, management resources, and organizations conducting research on COPD. | www.NECAcommunity.org (866) 229-2768 |
| National Jewish Medical and Research Center | Excellent website with extensive lung-related information. National Jewish is a world leader in pulmonary, allergic, and immune disorders. | http://www.nationaljewish.org (800) 222-5864 |
| National Lung Health Education Program (NLHEP) | This site, headed by Dr. Thomas Petty, is considered to be the foremost authority on COPD and related lung diseases. | www.nlhep.org |
| United States Environmental Protection Agency (EPA) | EPA provides extensive information and free publications for families and professionals on indoor air quality. Some resources are available in Spanish and other languages. | www.epa.gov/iaq (800) 438-4318 |

Selected Online Resources

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| Americans with Disabilities Act | Free Consulting Center | http://janweb.icdi.wvu.edu (800) 526-7134 |
| COPD Lung Profiler | Enables COPD patients and their physicians to make informed treatment decisions using information from evidence-based, peer-reviewed medical literature. | www.lung.org |
| NHLBI: Learn More Breathe Better® | COPD awareness campaign sponsored by of the Federal Government's National Institutes of Health. | www.nhlbi.nih.gov/health/public/lung/copd/index.htm |
| National Home Oxygen Patients Association (NHOPA) | A national organization that provides resources to improve the quality of life for home oxygen users. | www.homeoxygen.org (888) 646-7244 |
| The Pharmaceutical and Research Manufacturers of America | Conducts advocacy for public policies that encourage discovery of important new medicines for patients by pharmaceutical-biotechnology research companies. | www.phrma.org (202) 835-3400 |
| Portable Oxygen: A User's Prospective | Site by Pete Wilson, COPD patient. Includes a general overview and information on providers, oxygen types, traveling, flying, and conserving devices. | www.portableoxygen.org |
| Pulmonology Channel | Wealth of information on all types of lung disease, including COPD. Includes a video section, doctor finder, dictionary, news features, and more. | www.pulmonologychannel.com |
| Pulmonary Education and Research Foundation (PERF) | Provides help for those with chronic respiratory disease through education, research, and information. | www.perf2ndwind.org/index.html |

Selected Online Resources

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| Pulmonary Function Tests (PFTs) Explained | International Association of Fire Fighters' description of PFTs with explanations on the differences between spirometry vs. full PFTs, definitions, disease patterns, and interpretations. | www.iaff.org/hs/resi/pulmonary%20function%20tests.htm (202) 737-8484 |
| Second Wind Lung Transplant Association, Inc. | Support and education group focused toward those persons interested in or having received lung transplants. | www.2ndwind.org (888) 855-9463 |
| Traveling with COPD | An overview of tips for airline, cruise, train, and bus travel. | www.access-able.com/tips/oxy.html (800) 778-7953 |

Patient Assistance Programs and Related Resources

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| Area Agency on Aging | Provides information about community-based medication assistance programs | www.eldercare.gov (800) 877-1116 |
| Centers for Medicare & Medicaid Services (CMS) | The Prescription Drug and Other Assistance Programs section of Medicare.gov provides information on public and private programs that offer discounted or free medication, help with other health care costs, and prescription coverage Medicare health plans. | www.medicare.gov/pdphome.asp (877) 267-2323 |
| Drug Discount Cards | Some drug manufacturers offer drug discount cards for the elderly and disabled. | GSK's Orange Card: (888)672-6436 Eli Lilly's Card: (877) 795-4559 Novartis' Care Card: (866) 974-CARE Pfizer's Share Card: (800) 459-4156 Together Rx Card: (800) 865-7211 |
| Helping Patients | Interactive web site by PhRMA and 48 member companies. Assists patients in finding medication-assistance programs they may be eligible for. | www.helpingpatients.org (800) 762-4636 |
| RX Hope | Patient interactive assistance resource for pharmaceutical assistance programs. Supported by the pharmaceutical and Research Manufacturer's of America (PhRMA). | www.rxhope.com (908) 713-7600 |

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