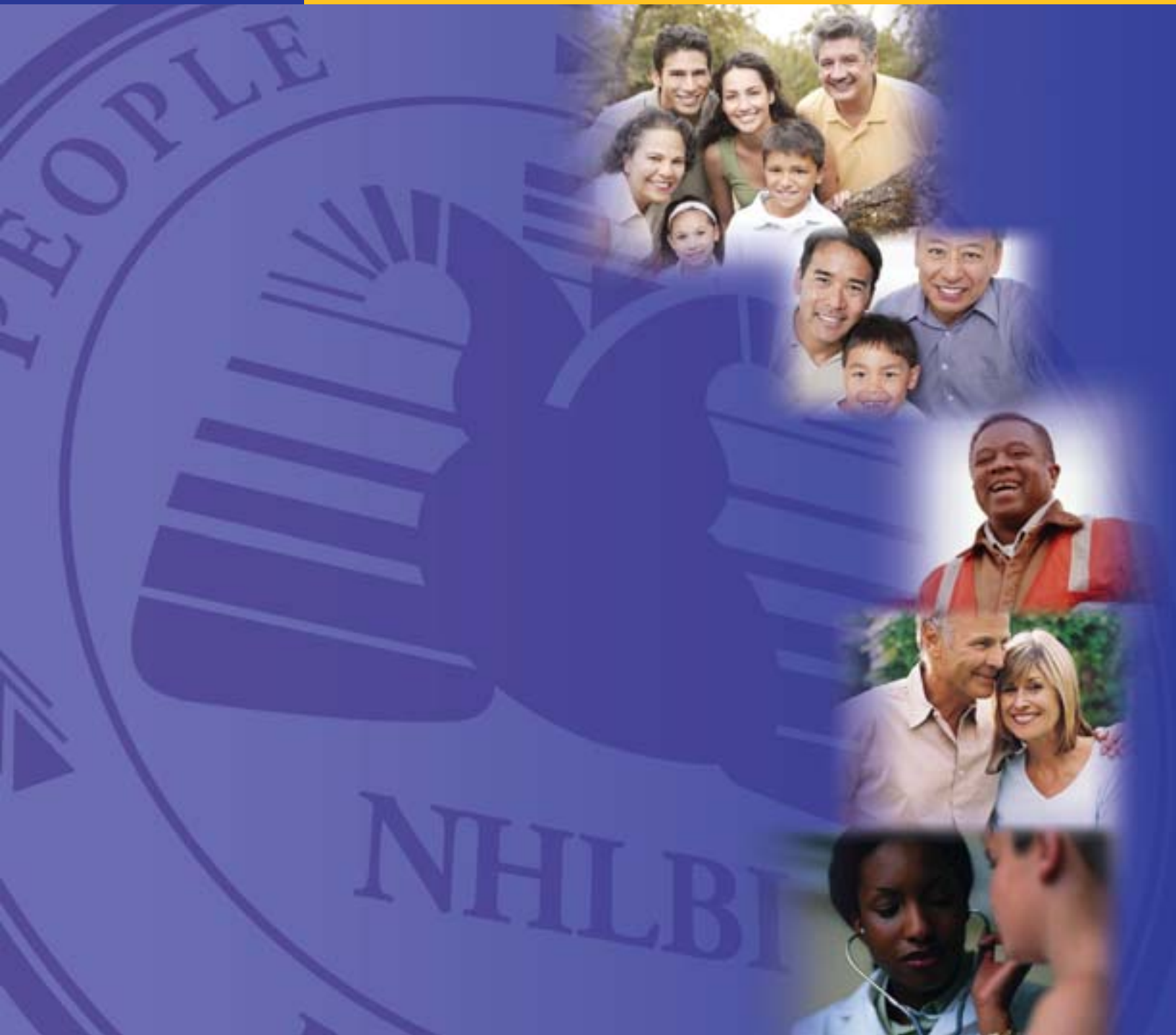


National Heart, Lung, and Blood Institute  
Education Strategy Development Workshop

# Chronic Obstructive Pulmonary Disease



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
National Institutes of Health  
National Heart, Lung, and Blood Institute



National Heart, Lung, and Blood Institute  
Education Strategy Development Workshop

# Chronic Obstructive Pulmonary Disease



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
National Institutes of Health  
National Heart, Lung, and Blood Institute

Administrative Use Only  
December 2005



# Contents

<b>Workshop Participants</b> .....	<b>v</b>
<b>Executive Summary</b> .....	<b>ix</b>
<b>Introduction</b> .....	<b>1</b>
<b>Presentations—Wednesday, September 22, 2004</b> .....	<b>3</b>
How Strategy Development Workshops Have Shaped NHLBI's National Education Programs? .....	4
Why a Strategy Development Workshop on COPD Is Needed? .....	4
COPD Education and Awareness: What Is Needed? .....	5
What Do Patients, Families, and At-Risk Individuals Need To Know? .....	8
Moving Forward Through Translation and Communication .....	8
The Current Environment: Management and Treatment .....	8
The Current Environment: Early Detection and Diagnosis .....	10
The Role of Patient Advocacy Organizations in COPD Awareness and Education .....	11
Risk Factors for COPD Other Than Tobacco .....	12
Tobacco as a Risk Factor for COPD .....	13
<b>Panel Discussions</b> .....	<b>15</b>
I. Living With COPD—Motivators and Barriers for Patients .....	15
II. Treating COPD—Facilitators and Barriers for Health Professionals .....	16
<b>Presentations—Thursday, September 23, 2004</b> .....	<b>19</b>
Best Practices for Developing a National COPD Education Program .....	20
Defining Needs and Opportunities .....	21
<b>Small Group Breakout Sessions</b> .....	<b>22</b>
Group 1: Target Audience: Health Care Professionals .....	22
Group 2: Target Audience: At-Risk and Early-Stage Patients .....	22
Group 3: Target Audience: Patients With Established and Advanced Disease .....	23
<b>Appendices</b> .....	<b>25</b>
<b>A. Agenda for Education Strategy Development Workshop         on Chronic Obstructive Pulmonary Disease</b> .....	<b>26</b>
Wednesday, September 22, 2004 .....	26
Thursday, September 23, 2004 .....	28
<b>B. Questions for Small Group Discussions</b> .....	<b>30</b>
<b>For More Information</b> .....	<b>inside back cover</b>



# Workshop Participants

## Workshop Cochairs

**Homer A. Boushey, M.D.**

*Immediate Past President*

American Thoracic Society

*Professor of Medicine, Department of Medicine*

University of California, San Francisco

San Francisco, CA

**John W. Walsh**

*President, CEO, and Cofounder*

Alpha-1 Foundation

Miami, FL

## Facilitator

**George I. Balch, Ph.D.**

Balch Associates

Oak Park, IL

## Participants

**Michael Ader, M.D.**

*Medical Director, Respiratory Care*

Hanover Hospital

Hanover, PA

**William Bailey, M.D.**

*Professor of Medicine and Director*

Lung Health Center

University of Alabama at Birmingham

Birmingham, AL

**Sidney S. Braman, M.D.**

*Professor of Medicine*

Brown Medical School

Providence, RI

**A. Sonia Buist, M.D.**

*Professor of Medicine*

Oregon Health and Science University

Portland, OR

**Richard Casaburi, M.D., Ph.D.**

*Director, Pulmonary Function, Respiratory, and  
Critical Care Physiology and Medicine*

Los Angeles County Harbor-

UCLA Medical Center

Torrance, CA

**Deborah Chase**

Chase Communications

New York, NY

**Ron Cook**

Emphysema Foundation

for Our Right To Survive

Morrow, GA

**Gerard J. Criner, M.D.**

*Professor of Medicine*

Temple Lung Center

Temple University

Philadelphia, PA

**Pam DeNardo**

Emphysema Foundation

for Our Right To Survive

St. Charles, IL

**Dennis E. Doherty, M.D., F.C.C.P.**

*Chief, Division of Pulmonary  
and Critical Care Medicine*

*Medical Director, Respiratory Care Services*

University of Kentucky

Chandler Medical Center

Lexington, KY

**James E. Douglas**

COPD International

Lexington, KY

**Janet Douglas**

Lexington, KY

**Gary Ferguson, M.D.**

*Director*

Pulmonary Research Institute  
of Southeast Michigan  
Livonia, MI

**Chip Gatchell**

Nashua, NH

**Audrey G. Gift, Ph.D., R.N., F.A.A.N.**

*Professor and Associate Dean*

College of Nursing  
Michigan State University  
East Lansing, MI

**Phyllis Greenberger, M.S.W.**

*President and CEO*

Society for Women's Health Research  
Washington, DC

**Lawrence Grouse, M.D., Ph.D.**

*Executive Director*

U.S. COPD Coalition  
Gig Harbor, WA

**Leslie A. Hoffman, Ph.D., R.N., F.A.A.N.**

*Professor and Chair,*

*Department of Acute/Tertiary Care*  
University of Pittsburgh School of Nursing  
Pittsburgh, PA

**Anne M. Holbrook**

*Senior Educational Learning Specialist*

SPRY Foundation  
Washington, DC

**Suzanne S. Hurd, Ph.D.**

*Scientific Director*

Global Initiative for Chronic Obstructive  
Lung Disease (GOLD)  
Gaithersburg, MD

**Barbara M. Kaplan, M.P.H., C.H.E.S.**

*Manager, Adult Lung Disease Programs*

American Lung Association  
Washington, DC

**Suzanne Lareau, R.N., M.S.**

*Pulmonary Clinic Nurse Specialist*

New Mexico VA Health Care System  
Albuquerque, NM

**Gretchen Lawrence, R.R.T.**

*Associate*

National Lung Health Education Program  
Dallas, TX

**Margaret Lester, R.N., M.S.N., F.N.P.**

*Director of Educational Programs*

National Respiratory Training Center  
Raleigh, NC

**Amy Maggio, M.S.**

*Managing Editor, COPD Digest*

COPD Foundation  
Chicago, IL

**Barry Make, M.D.**

*Director, Pulmonary Rehabilitation*

National Jewish Medical and Research Center  
Denver, CO

**Fernando J. Martinez, M.D., M.S.**

*Professor of Medicine*

Pulmonary and Critical Care Medicine  
University of Michigan  
Ann Arbor, MI

**Ray Masferrer, R.R.T.**

*Associate Executive Director*

American Association for Respiratory Care  
Irving, TX

**Ronald Moolenaar, M.D., M.P.H.**

*Epidemiologist*

Centers for Disease Control and Prevention  
Atlanta, GA



**Sydney Parker, Ph.D.**

*Vice President, Development and Outreach*  
American College of Chest Physicians  
Northbrook, IL

**Katherine Pruitt**

*Assistant Vice President, Program Services*  
American Lung Association  
Washington, DC

**John J. Reilly, M.D.**

*Associate Professor of Medicine*  
*Clinical Director*  
Pulmonary and Critical Care Medicine  
Brigham and Women's Hospital  
Harvard Medical School  
Boston, MA

**Ken Richmond**

Fairfax Station, VA

**Vlady Rozenbaum, Ph.D.**

COPD Alert  
Silver Spring, MD

**Robert Sandhaus, M.D., Ph.D.**

*Professor of Medicine*  
National Jewish Medical and Research Center  
Denver, CO

**E. Neil Schachter, M.D.**

*Professor of Medicine*  
Mount Sinai Medical Center  
New York, NY

**Frank Sciruba, M.D.**

*Associate Professor of Medicine*  
Division of Pulmonary, Allergy,  
and Critical Care Medicine  
University of Pittsburgh School of Medicine  
Pittsburgh, PA

**Edwin K. Silverman, M.D., Ph.D.**

*Assistant Professor of Medicine*  
Brigham and Women's Hospital  
Harvard Medical School  
Boston, MA

**Stuart Stoloff, M.D.**

*Clinical Professor*  
Family and Clinical Medicine  
University of Nevada School of Medicine  
Carson City, NV

**Byron Thomashow, M.D.**

*Clinical Professor of Medicine*  
Columbia University  
New York, NY

**Norbert Voelkel, M.D.**

*Professor*  
University of Colorado Health Sciences Center  
Denver, CO

**Barbara P. Yawn, M.D., M.Sc., F.A.A.F.P.**

*NHLBI Liaison*  
American Academy of Family Physicians  
*Assistant Editor, Patient Centered Care for COPD*  
*Director of Research*  
Olmstead Medical Center  
Rochester, MN

## **NHLBI Staff Members**

**Douglas Boyd**

*International Program Officer*  
Office of International Programs  
National Heart, Lung, and Blood Institute

**Thomas L. Croxton, M.D.**

*Medical Officer*  
Division of Lung Diseases  
National Heart, Lung, and Blood Institute

**Lawrence Friedman, M.D.**

*Acting Deputy Director*  
National Heart, Lung, and Blood Institute

**Robinson Fulwood, Ph.D., M.S.P.H.**

*Senior Manager for Public Health  
Program Development*  
Office of Prevention, Education, and Control  
National Heart, Lung, and Blood Institute

**James P. Kiley, Ph.D.**

*Director*  
Division of Lung Diseases  
National Heart, Lung, and Blood Institute

**Gregory J. Morosco, Ph.D., M.P.H.**

*Associate Director for Prevention, Education,  
and Control*  
National Heart, Lung, and Blood Institute

**Nancy J. Poole, M.B.A.**

*Senior Manager for Program Operations*  
Office of Prevention, Education, and Control  
National Heart, Lung, and Blood Institute

**Susan T. Shero, R.N., M.S.**

*Public Health Advisor*  
Office of Prevention, Education, and Control  
National Heart, Lung, and Blood Institute

**Lenee N. Simon, M.P.H.**

*Community Health Specialist*  
Office of Prevention, Education, and Control  
National Heart, Lung, and Blood Institute

**Ellen K. Sommer, M.B.A.**

*Public Health Advisor*  
Office of Prevention, Education, and Control  
National Heart, Lung, and Blood Institute

**Juliana J. Tu, M.S.**

*Community Health Specialist*  
Office of Prevention, Education, and Control  
National Heart, Lung, and Blood Institute

**Gail G. Weinmann, M.D.**

*Program Director*  
Division of Lung Diseases  
National Heart, Lung, and Blood Institute

# Executive Summary

## Background

In September 2004, the National Heart, Lung, and Blood Institute (NHLBI) convened a 2-day meeting to develop a national education strategy for chronic obstructive pulmonary disease (COPD), a progressive obstruction of the air passages of the lung that is not fully reversible by treatment. (See appendix A for the meeting's agenda.) COPD is the fourth leading cause of death in the United States and is growing in prevalence around the globe. From 1965 to 1998, the death rate from COPD grew 163 percent while death rates from all other major diseases fell. Approximately 15 million people in the United States have COPD, leading to \$15 billion in annual direct medical costs.

Symptoms include shortness of breath, persistent coughing, and excess mucous production. Patients are generally diagnosed in their 40s or later, sometimes after years of symptoms.

Smoking causes about 85 percent of COPD cases, but other environmental factors—such as fumes, gases, and dust—also play a role. Some occupations and certain industries, especially mining and manufacturing, raise a person's risk of COPD, as does the genetic predisposition of alpha-1 antitrypsin deficiency.

Some theories suggest that bacterial and viral infections help trigger COPD. It is likely that genetic factors also shape the risk for the disease, but researchers are just beginning to identify the genes involved.

## Overview of the Problem

Despite the prevalence of COPD, the public and those at greatest risk for the disease are largely unaware of it. Most people do not realize that COPD is a serious consequence of cigarette, cigar, and pipe smoking that can profoundly affect quality of life and lead to premature death.

Diagnosis of COPD can be made by spirometry, a simple test of lung function. Spirometry is underused, however, especially among primary care physicians. Treatments that relieve symptoms and improve quality of life, such as short- and long-acting bronchodilators and pulmonary rehabilitation, are available but are also underused. Unfortunately, no current treatments reverse the progressive loss of lung function in COPD, although smoking cessation has been proven to slow its course.

The myths and stigma that surround COPD hinder its diagnosis and treatment. Many physicians do not recognize the symptoms of COPD until late in its course, and then regard the condition as untreatable, progressive, and ultimately terminal. Attitudes of “blame and shame” too often accompany a diagnosis of COPD. Physicians and caregivers may blame patients for bringing the disease on themselves. The shame felt by patients fosters denial and delays seeking care. These negative attitudes contribute to underdiagnosis, undertreatment, and a general lack of awareness about COPD. It is true that no known treatment reverses or “cures” COPD, but now that it is known that smoking cessation slows progression and that treatments can relieve symptoms, prevent exacerbations, improve functional capacity, and enhance quality of life, the time is right to increase awareness about COPD and its risk factors, treatment, and prevention.

## Goals and Recommendations

The primary recommendation that emerged from the workshop deliberations was that NHLBI develop and implement an awareness campaign on COPD that simultaneously reaches those with the disease, those at risk, and health care providers. Additional workshop conclusions about the campaign included recommendations to:

- Communicate to patients, those at risk, and healthcare providers that COPD is a chronic, treatable disease.
- Aim to diffuse negative attitudes about COPD held by all audiences.
- Raise awareness about COPD signs and symptoms among those at risk as well as patients.
- Encourage the use of spirometry testing in the primary care setting.
- Encourage those diagnosed with COPD to take action to slow the progression of the disease.
- Encourage patients with severe COPD to take an active role in managing their treatment.

## Introduction

The National Heart, Lung, and Blood Institute (NHLBI) convened a 2-day Education Strategy Development Workshop on Chronic Obstructive Pulmonary Disease (COPD) on September 22-23, 2004, in Alexandria, Virginia. The purpose of the workshop was to bring together relevant stakeholders—COPD patients and caregivers, members of advocacy organizations, clinicians, representatives of National health organizations and coalitions, and Federal Government representatives—to identify what is currently being done to address COPD education issues and what gaps in education exist.

Workshop participants were tasked with making recommendations to NHLBI for education and awareness activities based upon presentations made at the workshop as well as their own knowledge and experiences.

Approximately 60 stakeholders attended the workshop and heard presentations by experts in COPD on the current environment relative

to COPD management and treatment; early detection and diagnosis; the role of patient advocacy organizations; and risk factors for developing COPD. In addition, a panel of patients and caregivers shared their personal experiences being diagnosed and treated for COPD. A second panel, comprised of health care providers, shared their experiences and perspectives on diagnosing and treating COPD. In small group break-out sessions, workshop participants defined the needs of target audiences and made recommendations for awareness and education activities for those audiences. Target audiences addressed in the small groups were health care professionals; at-risk and early stage patients; and patients with established and advanced disease.

The primary recommendation made to NHLBI at the conclusion of the workshop was to develop and implement a public awareness campaign on COPD that targets patients and those at risk as well as health care providers.



# Presentations

Wednesday, September 22, 2004



## Presentations

Wednesday, September 22, 2004

### How Strategy Development Workshops Have Shaped NHLBI's National Education Programs?

GREGORY J. MOROSCO, PH.D., M.P.H.

During the past 30 years, NHLBI has educated professionals, patients, and the public on pertinent public health issues through high-profile programs, including the National High Blood Pressure Education Program, the National Cholesterol Education Program, the National Asthma Education and Prevention Program, the NHLBI Obesity Education Initiative, and the NHLBI Women's Heart Health Education Initiative.

All of these programs share three characteristics:

- Messages are rooted in the best science.
- Education and communication efforts are tailored to appropriate audiences.
- Local and national partnerships help to expedite the delivery of the latest science-based information to improve public health.

The goal of this meeting is to develop a blueprint for health education and communication about COPD for patients, health professionals, and the public.

In 2001, NHLBI held a similar meeting for heart health and women to address the lack

of awareness of heart disease as the leading killer of women. That 2-day meeting spurred a hugely successful effort—The Heart Truth campaign symbolized by the red dress—the new national symbol for women and heart disease. The impact of the campaign is quickly becoming apparent. In 1997, the American Heart Association found that only 34 percent of women realized that heart disease was the #1 killer among women. In 2003, that figure jumped to 46 percent.

### Why a Strategy Development Workshop on COPD Is Needed?

JAMES P. KILEY, PH.D.

Ultimately, our goal is to improve the health of the Nation. Because COPD is consistently underestimated as a public health problem, the time has arrived to raise awareness of the disease and its treatments. One critical path to that goal is educating the public, patients, health professionals, and policymakers.

This burden is increasing. See Box 1. From 1965 to 1998, deaths caused by COPD have risen 163 percent. Turning this trend around will take a concerted effort, and we're at a critical point for doing so. NHLBI has a COPD clinical research network that is testing new treatments, and we need to ensure that the widest possible cross-section of patients benefits from these advances. To do that, we need an infrastructure for education that leverages partnerships and fills

#### Box 1: The burden of COPD is staggering and can be summarized by the "15s":

- 15 million patients in the United States
- 1.5 million emergency department visits annually
- 150 million days of lost work annually
- \$15 billion annually in direct medical expenses



the gaps in awareness. NHLBI can play a role, but we need guidance and input from everyone—researchers, policymakers, physicians, patients, and family members.

### **COPD Awareness and Education: What Is Needed?**

HOMER A. BOUSHEY, M.D.

Any successful COPD education program must build on our knowledge of the disease. Here is a brief outline of our understanding.

#### **What is COPD?**

COPD is characterized by airflow limitation due to airspace and airway disease that is only partially reversible by treatment. Physicians and the public use several labels to refer to COPD, including chronic bronchitis, chronic obstructive bronchitis, emphysema, and “smoker’s lung.”

Any education and awareness program will have to confront the issue of multiple names. Multiple labels confuse patients and complicate epidemiological research, making it difficult for researchers to pinpoint exactly how many people have the disease.

Although cigarette smokers are at high risk for COPD, few recognize it as a threat. The vast majority do not realize that they are nearly as likely to die from COPD as from lung cancer.

#### **What is the burden of COPD?**

COPD now ranks as the fourth leading cause of death in the United States, accounting for 114,000 deaths annually. This rate is rising in both males and females but is rising faster among women, as they recently passed men in total deaths from COPD. Globally, during the next 30 years, COPD will rise to become the third leading cause of death. However, there are still gaps in our epidemiological knowledge of COPD, especially in estimating the prevalence of undiagnosed disease.

#### **What causes COPD?**

The disease is attributed to an abnormal inflammatory response to repeated inhalation of harmful particles and gases, especially those in cigarette smoke. The size, density, and composition of particles and gases determine how harmful they are to the airways.

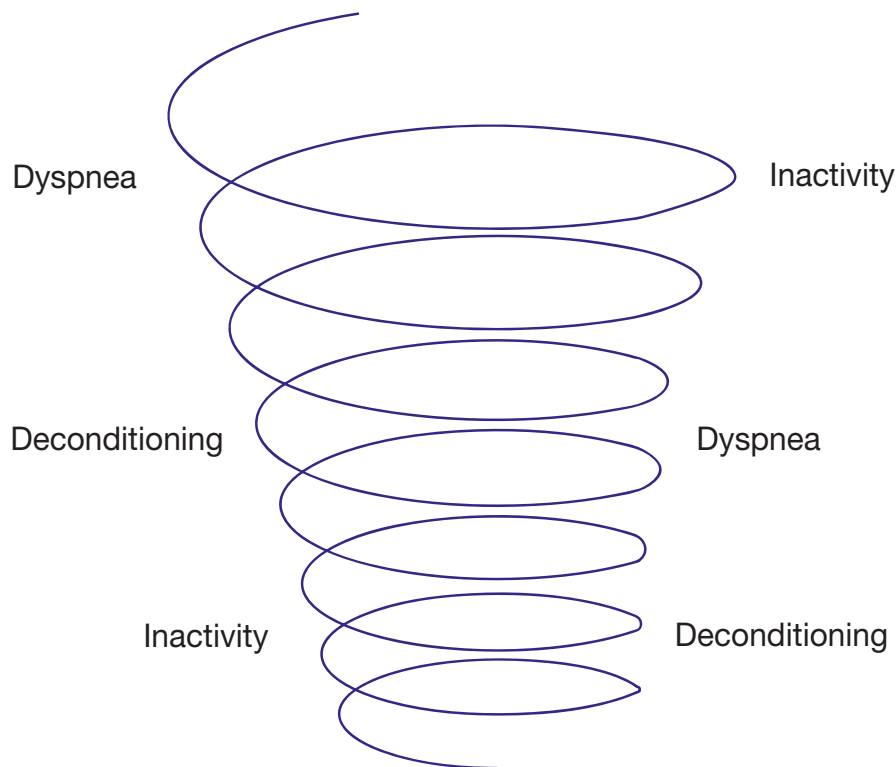
This broad understanding, though, is limited by enormous gaps in knowledge. Viral and bacterial infections might play a role, but evidence is limited. We have identified alpha-1 antitrypsin deficiency as a genetic risk factor for COPD but do not know the role of other genes in determining a person’s susceptibility.

#### **How can COPD be detected?**

The disease is easy to detect, but only if physicians have a high index of suspicion. One problem is that many physicians simply do not think of COPD or look for it. For that reason, the prevalence is probably grossly underestimated. Patients often fail to bring breathing problems to the attention of their physicians. Instead, they tend, often unconsciously, to modify their behavior to avoid shortness of breath.

Spirometry is a safe, accurate, and painless test. Unlike the devices used in the past, modern equipment is inexpensive, compact, and easy to use. Many physicians maintain outdated views of spirometry. They believe that the equipment is unwieldy, that the results are difficult to interpret, and that treatment decisions can be made just as easily on the basis of symptoms and a physical exam. All of these views are demonstrably false. Generally, physicians will only use spirometry if they believe a diagnosis will lead to a benefit. In patients with moderate or severe COPD, there is a proven benefit to diagnosis: It leads to treatment, and despite common misperceptions, effective treatments are available.

**Figure 1: Another Way of Defining Progression**



### **How does COPD progress?**

Gaps in our knowledge prevent a concrete answer, but we know that continued exposure to particles and gases that cause COPD accelerates its course. We also know that the course is punctuated by periodic exacerbations, most often caused by viral or bacterial infections of the bronchial airways. These account for great morbidity and cost, and occur more frequently in patients with severe COPD. Recovery from exacerbations of COPD may be prolonged, but their impact on the overall rate of loss of pulmonary function is unknown.

Progression of COPD can be defined as a descending spiral. See Figure 1. The disease leads to dyspnea, which leads to inactivity,

which causes deconditioning, which causes more dyspnea, and so on.

### **Can it be treated?**

Although treatment cannot fully reverse airflow obstruction, it can improve quality of life. Bronchodilators temporarily improve airflow obstruction and alleviate immediate symptoms; some drugs decrease the frequency of exacerbations; smoking cessation slows progression of the disease; and oxygen supplementation can prolong life. The only treatment effective against progression of the disease is smoking cessation. The only treatment proven to prolong life is oxygen supplementation in patients with oxygen insufficiency.

## Box 2: COPD Goals of Healthy People 2010

Goal	HP 2010 Target	Current Rate
Reduce COPD among adults.	1.5%	2.2%
Reduce death rate from COPD among all adults.	60 per 100,000	119.4 per 100,000

Pulmonary rehabilitation is another treatment option. While it does not significantly improve pulmonary function, it reduces symptoms, alleviates anxiety and depression, reduces hospitalization rates, improves exercise performance, and enhances overall quality of life.

Unfortunately, all of these treatments are underused. The public, patients, and physicians often believe that treatments are not useful. This is untrue. Although the treatments we have are not perfect, they help many patients.

### How are we doing?

Healthy People 2010 set two goals for COPD: to reduce the proportion of adults older than 45 whose activities are limited by chronic lung problems and to reduce deaths from COPD among all adults (See Box 2.). These goals will be hard to achieve since COPD develops and progresses insidiously, causing symptoms only when the loss of pulmonary function becomes severe enough to interfere with usual activities. There is thus a large reservoir of “preclinical” COPD patients who will add to the numbers of those diagnosed with COPD as the “baby boomer” population ages.

While we are not doing well in detecting patients with “preclinical” COPD, we are not

doing much better in caring for those who have it. The 2002 Confronting COPD Survey<sup>1</sup> interviewed 3,265 people with COPD and found that:

- 60 percent reported limitations in physical activities.
- 45 percent reported limitations in social activities.
- 36 percent of those under age 65 were unable to work.
- 13 percent had been hospitalized in the past year.

The survey also found that patients consistently underestimated the severity of their disease. For instance, of those whose symptoms were so severe they had trouble leaving the house, 36 percent said they had “mild or moderate” disease.

### Why are we doing so poorly?

One theory holds that patients, providers, and society are coconspirators in denial about the prevalence and severity of COPD. Our built environment<sup>2</sup> makes it easy to avoid symptoms. Many patients feel shame, blaming themselves for bringing on the disease. Time pressures on

<sup>1</sup> Rennard S, Decramer M, Calverley PMA, et al. Impact of COPD in North America and Europe in 2000: Subjects’ perspective of confronting COPD international survey. *Eur Respir J.* 2002;20:799–805.

<sup>2</sup> “Built environment” encompasses all of the buildings, spaces, and products created or modified by people. Also see <http://www.niehs.nih.gov/drcpt/be/home.htm>.

physicians and “therapeutic nihilism”—the belief that treatments do not work—lead to underdiagnosis and undertreatment.

### What can we do about it?

Facts are the best remedy for denial: COPD is common and is growing in prevalence; the burden is great and becoming greater; COPD is easy to diagnose; and treatments, although not perfect, are effective, especially for patients with moderate-to-severe disease.

Lessening the burden of COPD will require a broad, coordinated education strategy. Government commitment to and community involvement in a focused plan can push us toward our goals. For maximum impact, legislative, educational, research, and treatment initiatives must fit together logically.

### What Do Patients, Families, and At-Risk Individuals Need To Know?

JOHN W. WALSH

Many patients feel we are “on our own” with this disease. We need to know what a diagnosis of COPD means and what challenges lay ahead. Many of us are unsure where to turn for help. In talking with other patients, I’ve found that many are despondent and feel helpless.

Two surveys, *Confronting COPD*<sup>3</sup> and the *COPD Resource Network Needs Assessment Survey*<sup>4</sup>, show that patients do not feel well informed about treatment options. Many never or rarely see lung specialists. Awareness of pulmonary rehabilitation and its benefits is low, and dissatisfaction with treatment is high.

We need direction, advice, and education. We know that patients connected with advocacy groups fare better and feel more informed. “The more aware, the better the care” could be our

slogan. Unfortunately, 83 percent of patients are unaware that patient groups are available.

Although the Internet harbors much useful information and support for COPD, approximately 80 percent of patients report little or no access to the Internet. That means we need to reach patients through other channels. Patient education improves outcomes and reduces costs. The desire and need for more and better information is extremely high, but we’ve got a long way to go.

### Moving Forward Through Translation and Communication

LAWRENCE FRIEDMAN, M.D.

Dr. Friedman said that we need to pay more attention to translation and communication. We’ve done that with high blood pressure and other health risks. Clearly, the whole issue of translation—getting what we know out into the community—is something we have not paid enough attention to in COPD.

The NHLBI invites your input and guidance. How can we proceed? What are the appropriate ways? What information do we need to learn how to communicate better?

### The Current Environment: Management and Treatment

FERNANDO J. MARTINEZ, M.D., M.S.

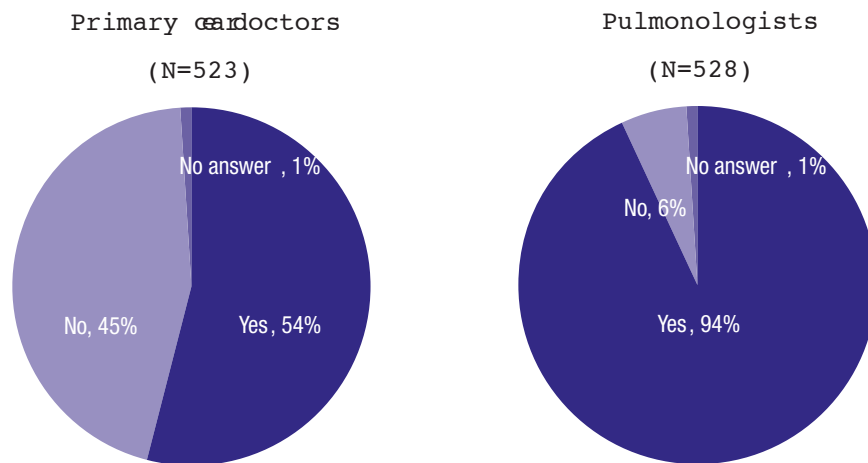
During the past 5 years, there has been an explosion of professional guidelines for the management and treatment of COPD. However, awareness among physicians is low: Approximately 45 percent of primary care physicians and 6 percent of pulmonologists do not know that COPD guidelines exist. See Figure 2.

The various guidelines are similar to some degree: 98 percent present a definition of

<sup>3</sup> Rennard S, Decramer M, Calverley PMA, et al. Impact of COPD in North America and Europe in 2000: Subjects’ perspective of confronting COPD international survey. *Eur Respir J*. 2002;20:799–805.

<sup>4</sup> Barr RG, Celli BR, Martinez FJ, et al. Physician and patient perceptions in COPD: The COPD Resource Network Needs Assessment Survey. *Am J Med*. 2005;118:1415.e9–1415.e17.

**Figure 2: Awareness of Professional Guidelines for COPD**



Are you aware of any professional guidelines for the diagnosis and management<sup>4</sup> of COPD?

COPD; 98 percent recommend lung rehabilitation; and 83 percent recommend spirometry for diagnosis.

However, physician adherence is not uniform. When diagnosing COPD, only 32 percent of primary care physicians and 79 percent of pulmonologists state they use spirometry for diagnosis all the time. That figure should be 100 percent. Primary care physicians report they refer patients for lung rehabilitation routinely only 19 percent of the time, and with pulmonologists, the figure is 54 percent.

Not all of the guidelines are well constructed and easy to use, both of which are key features for use by physicians. The Global Initiative for Chronic Obstructive Lung Disease (GOLD)

guidelines are probably the most comprehensive and most widely used. They are evidence based, clearly written, credible, relevant to how physicians practice, and easy to follow.

Disease management is a comprehensive approach under study for reducing the impact of COPD. In Quebec, seven hospitals recently completed a prospective, randomized trial of 191 COPD patients older than 50 with stable disease.<sup>5</sup> Half of the patients received usual care, and the other half received education in self-management of the disease. The number of hospital admissions among the educated group dropped 40 percent, as did the number of emergency department visits. Clearly, a straightforward education strategy can be effective.

<sup>5</sup> Bourbeau J, Julien M, Maltais F, et al. Reduction of hospital utilization in patients with chronic obstructive pulmonary disease: a disease-specific self-management intervention. *Arch Intern Med.* 2003;163:585-91.

A similar program, stratified by disease severity, at the National Jewish Medical Research Center also included aggressive patient education.<sup>6</sup> After 6 months, patients who received the education reported 77 percent fewer missed days of work and 56 percent fewer hospitalizations.

The Centers for Medicare & Medicaid Services (CMS) recently launched a large chronic care improvement program at 10 regional centers. One or two of these centers will be studying COPD for 3 years, with the goal of improving treatment quality, patient satisfaction, and disease outcomes. Advocacy by patients and physicians to raise awareness within CMS is key to reimbursement and widespread adoption of COPD management techniques.

### **The Current Environment: Early Detection and Diagnosis**

DENNIS E. DOHERTY, M.D., F.C.C.P.

Any COPD education campaign should include messages about the routine use of spirometry, because it is the best tool we have for early diagnosis and monitoring therapies. It is inexpensive and simple. With the newer user-friendly, hand-held office spirometers, an accurate reading of lung function can be obtained in the office setting within a few minutes. Spirometry can be easily administered by nurses or other office staff while they record other vital signs of patients. Newer machines are pocket size, cost between \$800 and \$1,000, and easily interface with personal computers to generate printouts for placement in the patient's chart and to document eligibility for reimbursement.

Advocating screening for everyone is probably not a cost- or time-efficient solution. The high number of negative results can lead to disillusionment about the usefulness of spirometry.

Instead, selective early detection should be used in those patients identified to be at risk for COPD; education campaigns should promote spirometry for at-risk individuals. Because 85 percent of COPD is caused by smoking, any current or former smoker who is 45 years or older should have spirometry. In addition, patients of any age with one or more of the cardinal signs and symptoms of COPD (chronic cough, excess mucous production, dyspnea on exertion out of proportion to that expected for the activity, or wheezing) should have spirometry. If spirometers are available in every primary care office, we will have a better chance of identifying and appropriately treating COPD earlier, potentially leading to a reduction in the increasing morbidity and mortality associated with this disease.

If we decide to put spirometers in places besides physicians' offices—much like high blood pressure machines in drug stores—we have to carefully craft the messages to accompany the testing. What do you tell those with normal results? To stop smoking. What do you tell those with abnormal results? To stop smoking and to utilize the therapies recommended by their clinicians.

We can't wait for patients to come into our offices and complain of symptoms. Many patients with COPD slowly modify their lifestyle over the years to do less demanding activities that do not lead to shortness of breath. Instead, we need to ask them probing questions to identify what their activities were years ago and determine whether their activity is less than that of their peers. Only then will we reach them when they still have subclinical disease in their minds. We certainly can't wait until they have a chest x ray that is grossly abnormal showing hyperinflation and pulmonary hypertension—this is much too late.

<sup>6</sup>Endicott L, Corsello P, Prinzi M, et al. Operating a sustainable disease management program for chronic obstructive pulmonary disease. *Lipp Case Management*. 2003;6:252–64.

The intensive care unit is the worst place to initially diagnose COPD—it needs to be done much earlier in the offices of primary care clinicians at a time when mild or moderate disease can be identified.

Right now, reimbursement is the biggest obstacle to widespread use of spirometry. But as patients begin to request to “Know Their Numbers” (lung age, FEV<sub>1</sub>, FEV<sub>1</sub>/FVC ratio) more and providers begin to perform spirometry in those at risk for COPD more often, the evidence-based data on the effectiveness and utility of earlier detection of COPD will accumulate and push insurers toward better reimbursement.

Ideally, we can raise awareness of COPD, much as high blood pressure awareness campaigns have raised awareness of stroke and heart disease. Teaching at-risk individuals to ask for spirometry and making it easy for clinicians to perform the test and interpret the results are the best strategies for making the determination of lung function via spirometry the fifth vital sign. The slogan of the National Lung Health Education Program since its inception in 1997 has been, “Test your lungs, know your numbers.” In practice, these are the numbers derived from spirometry—lung age for patients, and FEV<sub>1</sub> and FEV<sub>1</sub>/FVC ratio for clinicians.

### **The Role of Patient Advocacy Organizations in COPD Awareness and Education**

PAM DENARDO

The first principle of patient advocacy is that without a plan and a goal, you go nowhere fast. The landscape is now filled with patient advocacy groups for COPD, but the lack of common goals and messages hinders their power.

The second principle of patient advocacy is that educated patients are the best vehicle for spreading further education and awareness of COPD. Patients listen to and respect the opinion of other patients. The sympathy amongst patients cannot be found anywhere else.

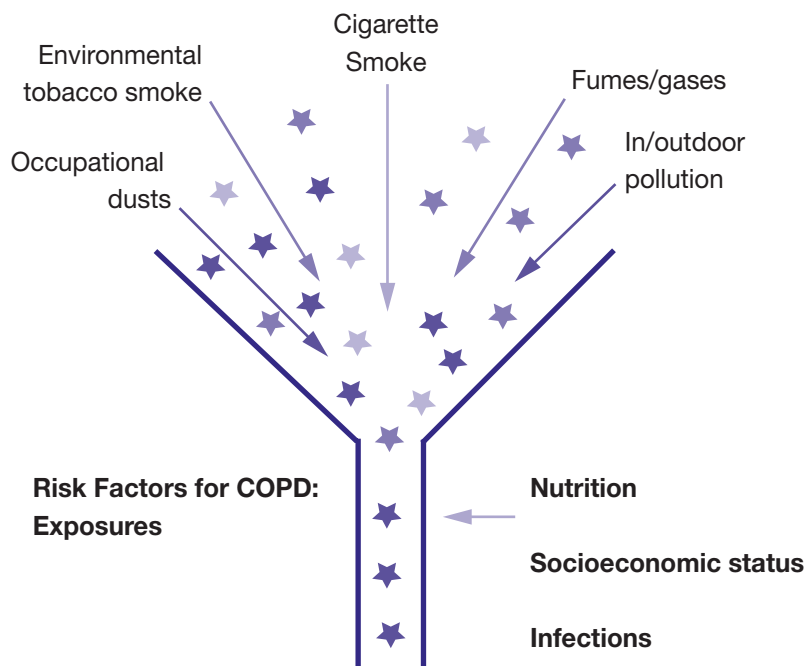
After my diagnosis, I went online and found many COPD advocacy groups. I joined Emphysema Foundation for Our Right to Survive (EFFORTS), and we wrote letters to local, State, and Federal politicians. We also sent newsletters to other support groups and promoted ourselves to the media. Again, all of these strategies help, but we are hindered by the lack of unity.

In traveling throughout my home State of Illinois, I've found that the need for education is greatest in small towns and rural areas. The lack of awareness of pulmonary rehabilitation, in particular, is deplorable. One doctor told a patient that “he wasn't sick enough” for it. Another patient was told he was too sick. One man received an erectile dysfunction medication and a short-acting bronchodilator, and that was it.

All of this leads to a fatalistic attitude. Many patients simply accept their fate and do nothing. Others go into denial and tell no one. Some of us feel shame. All of us who smoke have to put up with “I told you so”—even some physicians have that attitude.

Any education effort needs to start with clinicians. We need to eliminate shame and guilt, because educated, well-adjusted patients automatically become the generators of even greater awareness and action. With our strength in numbers, the COPD patient community now needs unity and guidance.

**Figure 3: Risk Factors for COPD**



### Risk Factors for COPD Other Than Tobacco

A. SONIA BUIST, M.D.

COPD is a disease defined by classic gene-environment interactions. A number of possible genetic risk factors have been suggested, but other than alpha-1 deficiency, none has been confirmed. It is likely that many genes are involved, and clarifying their roles will be difficult.

We do know what environmental exposures increase risk for COPD. Tobacco smoke is the most important. With children, environmental or secondhand smoke may be important. Chronic exposure to fumes (biomass fuels), indoor pollution, and dust increases the risk

for COPD. However, we still have no idea what role nutrition plays in early development of the disease, and we do not understand why it is more prevalent in lower socioeconomic classes. See Figure 3.

Occupation can be a risk factor, and recently more attention has been paid to it. The Third National Health and Nutrition Examination Survey (NHANES III 1988–1994)<sup>7</sup> identified the following occupations as at-risk for COPD: freight, stock, and materials handlers; records processors; transportation sector workers; machine operators; construction workers; and waiters and waitresses. Industries with the highest risk for COPD include rubber, plastics, and leather manufacturing; utilities; textile mills;

<sup>7</sup>Hnizdo E, Sullivan PA, Bang KM, Wagner G. Association between chronic obstructive pulmonary disease and employment by industry and occupation in the U.S. population: A study of data from the Third National Health and Nutrition Examination Survey. *Am J Epidemiol.* 2002;156:738–46.



### Box 3: Effectiveness of Smoking Cessation Interventions<sup>8</sup>

Intervention	Increase in Cessation Rate
Brief physician contact	2–3%
Group counseling	3.1–10%
Nicotine gum	6.6–8%
Bupropion (300 mg/day)	10–13.2%
Nicotine nasal spray	12–16.6%

and the armed services. However, research has not yet identified a common risk factor, if one exists, among these occupations and industries. NHANES III found that 19.2 percent of COPD is attributable to occupational risk and that 31.2 percent of COPD occurs in people who have never smoked. These figures are significantly higher among Mexican Americans, but we do not understand why.

Strategies for prevention should look at the entire lifespan, from prenatal to old age. Specific interventions at critical points can decrease risk. For instance, maternal smoking may increase lifetime risk for the baby. Environmental tobacco smoke and infections are risk factors for children. In adolescence, active smoking is added to the picture, and finally, in the adult years, occupation can become a risk.

The National Institute for Occupational Safety and Health has developed standards and educational materials for at-risk workplaces. Standards include exhausting particles wherever possible, providing workers with masks, and educating workers on reducing exposure.

In short, COPD is a response to everything that a person ever breathes. Reinforcing this message

can help people avoid situations that exacerbate their risk.

#### Tobacco as a Risk Factor for COPD

WILLIAM BAILEY, M.D.

Because COPD is a slowly developing disease, we have to confront a sobering fact: If every smoker quit today, the incidence of COPD would continue to rise until 2020. With that said, it is important to realize that smoking cessation is the single most effective and cost-efficient intervention for reducing the risk of COPD and halting its progression. See Box 3.

Smokers with COPD average 20 cigarettes per day for 20 years (20 pack-years). They may develop symptoms in their 40s, often dyspnea, sputum production, or an acute chest illness, but they frequently ignore these symptoms. At first, their shortness of breath worsens only when they exert themselves. They also may have a history of wheezing that may lead to a false diagnosis of asthma.

Providers need to know that brief smoking cessation counseling is effective. Practical counseling (e.g., how to deal with cravings) and social support are particularly effective. Every tobacco user should be offered counseling

<sup>8</sup> Marlow SP, Stoller JK. Smoking cessation. *Respir Care*. December 2003;48(12):1238–56.

during every visit to a health care provider. Approximately 70 percent of smokers are ready to quit, but they need to know how.

Although these interventions are effective, physicians often feel they do not have enough time to counsel patients about smoking cessation and that patients “do not want to hear about it.” However, a recent Mayo Clinic study<sup>9</sup> found that patients advised to quit during their last office visit were more satisfied with their physicians. The Public Health Service guidelines published in 2000 found that very brief counseling can increase tobacco abstinence rates.

When physicians want to counsel patients about smoking, they should personalize the message as much as possible. The five A's help to remind us

of the appropriate steps for health care providers:

- ASK about tobacco use.
- ADVISE them to quit.
- ASSESS their willingness to quit.
- ASSIST in quitting.
- ARRANGE for followup.

Discovering impaired lung function or receiving a diagnosis of COPD can be devastating to patients, but these can also provide opportunities for smoking cessation. In fact, they may be the most teachable moments—the best times to help patients quit smoking.

<sup>9</sup>Solberg LI, Boyle RG, Davidson G, Magnan SJ, Carlson CL. Patient satisfaction and discussion of smoking cessation during clinical visits. *Mayo Clin Proc.* 2001;76:138–43.

## Panel Discussions

### Panel Discussion I: Living With COPD—Motivators and Barriers for Patients

FACILITATOR: GEORGE I. BALCH, PH.D.

PARTICIPANTS: JAMES E. AND JANET DOUGLAS, KEN RICHMOND, PAM DENARDO, AND CHIP GATCHELL

This discussion session featured four patients and one caregiver (a spouse) who discussed their experiences with COPD. Dr. Balch, the facilitator, concentrated on bringing out shortcomings in how patients were diagnosed and treated. He also asked what helped patients get motivated to seek better treatment.

#### When did the light bulb go on that something was wrong?

The patients all felt they could have been diagnosed earlier, had they and their physicians been looking for COPD. Two patients said that pneumonia brought them to the doctor's office, at which point they were finally diagnosed with impaired lung function after years of shortness of breath. A third patient felt short of breath while golfing. "I went to the clinic," he said, "but they told me that this happens to a lot of people. So I wrote off my shortness of breath as due to not exercising and smoking too much. I didn't find out it was COPD until 3 years later."

The fourth patient had a long bout of recurring lung infections. His physician said it might be asthma and gave him an inhaler. Finally, after 13 or 14 bouts of bronchitis with coughing, wheezing, and shortness of breath, he told his physician that he wanted the test for alpha-1 deficiency. The physician replied that at 32, the patient was too young to have COPD but finally ordered the test, which was positive for alpha-1 antitrypsin deficiency.

#### What were you told to expect from the disease?

None of the patients had heard about COPD before their diagnosis. One patient said, "I just heard 'Blah, blah, blah,' until he said 'end-stage.' And then he said there was nothing he could do for me."

"To this day," said another patient, "my doctor has still never used the term 'COPD.'"

#### What keeps you going?

The caregiver said that sharing information and support with others in her situation is vital. Even with cancer, she said, patients have a chance of surviving their disease. "But with this, it's zero. It makes it very hard sometimes."

The youngest patient said he was still in denial. His lung function is relatively high (61 percent). He still plays tennis and golf. Another patient exercises every morning. "Attitude is medication, too," she said.

#### What could you have known earlier that would have made a difference?

"If I had known as a teenager [that I had alpha-1 deficiency], I would have made different choices," said one patient. The others said they would have quit smoking earlier if they thought they had COPD.

#### What about pulmonary rehabilitation? How do you manage it?

Three of the patients had tried or were still practicing pulmonary rehabilitation. Motivated patients who can afford it, or whose insurance covers it, usually attend several hours of rehabilitation each week. "But there are an awful lot of people," said one patient, "who do their 12 weeks and go home. Nobody knows if they keep up with it." Another said that after he stopped rehabilitation, he went downhill

quickly. He then vowed to keep up with rehabilitation. Short hours at the facilities can prevent patients from taking full advantage.

### **Who or what has been the best purveyor of information about this disease?**

All of the patients said that they were self-motivated and learned most of what they know about COPD on their own. Their internists or primary care physicians sometimes provided basic information. A few patients, feeling their physicians were not well informed, gave them newsletters and other information they had tracked down. Internet support groups pointed some of the patients to good information. Several said that their pulmonary therapist provided the most thorough, practical information about how to live with COPD.

### **Panel Discussion II: Treating COPD—Facilitators and Barriers for Health Professionals**

**FACILITATOR:** GEORGE I. BALCH, PH.D.  
**PARTICIPANTS:** SUZANNE LAREAU, R.N., M.S.,  
GRETCHEN LAWRENCE, R.R.T., STUART STOLOFF,  
M.D., AND BYRON THOMASHOW, M.D.

Dr. Balch facilitated this group session, which examined the role of health professionals in diagnosing and treating COPD. Again, the focus was on barriers to effective care; however, this time, the perspectives came from a primary care physician, a pulmonologist, a nurse, and a respiratory therapist.

### **When a patient comes in, how do you make a diagnosis?**

Dr. Stoloff, a primary care physician, said that the time crunch faced by physicians decreases the odds that they will ask about shortness of breath or other COPD symptoms: “It’s not uncommon for a person with COPD to be talking to me about diabetes, heart disease, depression, arthritis. And you’re supposed to get through all of that in a very short period.”

With COPD, he said, unlike other prevalent diseases, physicians do not have a quick checklist of questions to ask. “We’ve not done a good job of learning how to quickly identify and deal with it,” Dr. Thomashow agreed.

### **Which factors facilitate treatment, and which make it harder?**

Ms. Lareau, a nurse, said that patients have difficulty with the concept of around-the-clock treatment. That is, they may have to use their inhaler or take a pill four or more times a day, but they are hesitant to do that or fail to integrate it into their daily routines. Dr. Stoloff agreed that medication adherence is a problem, as patients today are less likely to “take responsibility or ownership” of their disease than patients he saw a decade ago.

Ms. Lawrence, a pulmonary therapist, said that patient attitude makes a major difference and reimbursement is a major problem. “Few are willing to pay for rehabilitation, even though everyone agrees it helps. In the Veterans Administration system, physicians and therapists do it on their own time, so to speak.”

### **As health professionals, what information are you missing?**

Dr. Stoloff said that physicians need information on “who pays for what.” Patients who cannot afford some expensive medicines can get them for free through compassionate care programs at drug companies, but patients and physicians need to know which forms to complete.

Others concurred, saying that simple charts of local pulmonary rehabilitation programs, their costs, and what forms of reimbursement they accept would greatly enhance the odds of physicians and patients following through with rehabilitation.

The participants said that basic written materials—pamphlets or other handouts, worksheets, and booklets—are vital. The materials need more lay-level information about what COPD is, what the patient can expect, which treatments are available, and so on. Internet searches bring up a lot of information on COPD, said Ms. Lareau, but much of it is not patient friendly.

**What about diagnosis and spirometry?  
What barriers prevent wider use of it?**

Medical schools fail to teach spirometry, said Dr. Thomashow. During residency, a pulmonary rotation is generally an elective,

not a requirement. Even then, “It’s more about learning ventilators and helping the really, really sick people.” The panelists all advocated teaching spirometry during medical school. “Even fitting 5 or 10 minutes in somewhere would be a great help,” said Dr. Stoloff.

Ms. Lawrence said that COPD advocates are losing a valuable opportunity to educate patients in waiting and examination rooms: “We could put a few basic questions and facts about spirometry on a poster and just put them up everywhere. Say, ‘If you answer yes to any of these questions, ask your doctor about spirometry.’ ”



# Presentations

Thursday, September 23, 2004



# Presentations

Thursday, September 23, 2004

## Best Practices for Developing a National COPD Education Program

GEORGE I. BALCH, PH.D.

The problem is clear: Too many people with COPD go undiagnosed; others get diagnosed late; and when they are diagnosed, they do not know what to expect, suffer needlessly, have needless limitations on their lives, and die too early.

How can a national health education program help? It can promote prevention and management of a disease by working at the most appropriate levels—individual, family, community, and society—for each problem.

Goals for a national education program can include informing and empowering people, mobilizing community partnerships, supporting individual and community health efforts, and promoting healthy lifestyles.

Components of a national education program can include media campaigns; partnerships among many groups; professional education activities, such as disseminating treatment guidelines and other tools; and patient education activities, such as tools that explain what to expect and how to manage the disease.

A national education program should facilitate consensus on diagnosis and treatment and translate science into products and messages. At the same time, to be successful, a national education program cannot ignore the science of the disease or the realities of consumers and health professionals.

When developing messages, target audiences need to be identified and understood. Desired outcomes for each audience must be identified. Only then can programs be developed to reach these audiences.

Target audience profiles should include:

- Demographics, including location, age, gender, race/ethnicity, and occupation.
- Psychographics, including values, interests, beliefs, routines, and investments of time and attention.
- Favored channels. What do they watch? Who do they listen to and interact with?
- Credible sources. Whom do they trust?
- Potential intermediaries (i.e., groups and organizations they relate to), including sports teams and community activist groups.

Desired outcomes for patients can include:

- More awareness of symptoms and the course of the disease.
- Changes in key attitudes, such as the importance of starting treatment immediately.
- Changes in specific behavior, such as seeking a diagnosis earlier, encouraging others to seek a diagnosis, and working with health professionals on a plan of action.

Desired outcomes for health professionals can include:

- Enhanced knowledge about the disease, including how to diagnose and treat it.
- Changes in attitudes about the relevance of diagnosis and treatment. COPD can be found early, and it can be treated.
- Destigmatizing COPD. It is not the patient's fault.
- Changes in behavior, including increased spirometry testing and increased questioning of patients.



In addition, a national education program can help build partnerships by increasing the perceived relevance and importance of COPD. It can place COPD on the agendas of decisionmakers, both corporate (e.g., Health Maintenance Organizations) and public (e.g., Congress).

Audiences need to be reached at critical or teachable moments, when they are most likely to pay attention to one or two key messages. They need information that they can immediately apply to themselves. For instance, a morning radio advertisement might say, “Did you cough last night? If so, ask your doctor about COPD.”

Channels to reach each audience must be cultivated. Potential channels include the U.S. mail, e-mail, television, radio, magazines, medical journals, Web sites of the National Institutes of Health (NIH), and interactions among patients and health professionals. To maximize efficiency, existing channels should be tapped first.

Finally, coordination, timing, and sustainability are critical. Messages to each audience must be consistent and mutually reinforcing, and they must reach each audience at the proper moment. Consider the disaster of millions of patients rushing to their physicians about

COPD, only to discover that health professionals have not received any information or tools. There’s nothing worse than great advertising without any product on the shelf. To be successful, a program must continue long enough, and be self-aware enough, to iron out the kinks and weather media sensations and the disease-of-the-moment syndrome. Only then will it penetrate deeply enough and spread far enough to make a true impact.

### **Defining Needs and Opportunities**

GEORGE I. BALCH, PH.D.

During a brainstorming session prior to the small group breakout sessions facilitated by Dr. Balch, participants voiced views on past health education campaigns, paying close attention to strategies that they deemed particularly well-crafted. Dr. Balch and workshop participants discussed the following two questions:

1. What health education campaigns have effectively reached the public in general and patients in particular? What made these strategies effective?
2. What materials and strategies should be considered for reaching health care professionals?

## Small Group Breakout Sessions: Defining Needs of Target Audiences and Making Recommendations for Awareness and Education Activities

Attendees were assigned to one of three groups and were tasked with developing messages and strategies for reaching three specific target audiences: health care professionals, at-risk and early-stage patients, and patients with established and advanced disease. Each group then reported back to the entire meeting. (See appendix B for an account of questions for the small group discussions.)

### Group 1. Target Audience: Health Care Professionals

This group emphasized positive messages. Physicians, nurses, respiratory therapists, and other health care professionals need to hear that COPD is preventable and treatable. It is not a “dead-end” diagnosis. Because many guidelines exist, NHLBI should not invest in developing new guidelines. Rather, the Institute should package existing guidelines in an easy-to-use manner.

The COPD Coalition (a partnership of patient and physician groups) and the Centers for Disease Control and Prevention (CDC) can help deliver the key messages defined by the acronym COPD:

- Consider COPD. The perception of COPD needs to change. It is a chronic disease that needs constant management. It is vital to convince health care professionals that it is possible to slow progression and improve quality of life.
- Obtain spirometry. Primary care physicians need to be trained in and encouraged to use spirometry. They need tools that tell them how to perform and interpret spirometry. Training should start in medical school and continue throughout a physician’s career.
- Prevent progression. Health care professionals should counsel smoking cessation and pulmonary rehabilitation during every patient interaction.

- Do active management. Physicians and other health care professionals need guides to pulmonary rehabilitation resources (e.g., a Web site could list rehabilitation centers by ZIP code). Disease management works best when developed as a system: Receptionists can point patients to basic information, nurses can inquire about symptoms, and physicians can encourage active participation in treatment.

### Group 2. Target Audience: At-Risk and Early-Stage Patients

This group defined its target audience as people over age 40 with risk factors and people of any age with symptoms such as shortness of breath and regular wheezing and coughing. All people in this target audience need to know what COPD is and what it means for their future. They need to hear that COPD can be treated. They need to be spurred to seek their physicians and ask about COPD and spirometry. Their response to education messages should be, “Hey, that sounds like me.”

Many partners can reinforce these messages. Pharmaceutical companies spend millions of dollars on direct-to-consumer advertising. Patient support groups have already developed networks to reach early-stage patients. Health insurers can include articles on COPD in their monthly newsletters. The Secretary of the U.S. Department of Health and Human Services and the Office of the Surgeon General can place COPD on the national agenda by issuing reports and holding press conferences. Children can be taught about COPD at school.

Channels to reach this group include the mass media, direct-to-consumer advertising, patient support group mailings and Web sites, NIH mailings and Web sites, insurance company newsletters, and billboards and other advertising.

### **Group 3. Target Audience: Patients With Established and Advanced Disease**

This group felt that patients who visited their physicians after an exacerbation were at a critical, teachable moment. Patients need to know that COPD is not a “death sentence”; that it can be slowed if they stop smoking; and that environmental risk factors, such as dust, smoke, and gases, can exacerbate the disease. They need to be encouraged to develop and stick to a health maintenance plan that includes vaccinations, medication adherence and management, exercise and pulmonary rehabilitation, and mental health support and, if necessary, treatment. Messages should be positive, as proposed in the acronym **HELP**:

- Have a hopeful outlook.
- Expect more.
- Learn everything you can about COPD.
- Participate in care.

Channels to reach this audience include the mass media; NIH and patient support group Web sites and e-mail lists; and pamphlets, booklets, flyers, posters, and videos distributed at primary care and specialist physicians’ offices.



## Appendices

- A: Agenda for Education Strategy Development Workshop on Chronic Obstructive Pulmonary Diseases (COPD)
- B: Questions for Small Group Discussions



## Appendix A. Agenda for Education Strategy Development Workshop on Chronic Obstructive Pulmonary Disease (COPD)

**Wednesday, September 22, 2004**

<b>8:15–9:00 a.m.</b>	<b>Registration and Continental Breakfast</b>	
<b>9:00–9:15 a.m.</b>	<b>Welcome and Introduction</b>	
	<ul style="list-style-type: none"> <li>• Welcome from NHLBI</li> <li>• How Strategy Development Workshops Have Shaped NHLBI's National Education Programs ?</li> <li>• Why a Strategy Development Workshop on COPD Is Needed?</li> </ul>	<p>Lawrence Friedman, M.D. Gregory Morosco, Ph.D., M.P.H.</p> <p>James P. Kiley, Ph.D.</p>
<b>9:15–9:35 a.m.</b>	<b>COPD Awareness and Education: What Is Needed?</b>	Homer A. Boushey, M.D.
	<ul style="list-style-type: none"> <li>• What does the science show?</li> <li>• Where are the gaps?</li> <li>• What do physicians and other health care providers need to know?</li> </ul>	
<b>9:35–9:45 a.m.</b>	Questions and Answers	Group
<b>9:45–10:05 a.m.</b>	<b>What Do Patients, Families, and At-Risk Individuals Need To Know?</b>	John W. Walsh
	<ul style="list-style-type: none"> <li>• Confronting COPD in America results</li> </ul>	
<b>10:05–10:15 a.m.</b>	Questions and Answers	Group
<b>10:15–10:30 a.m.</b>	BREAK	
<b>10:30–11:15 a.m.</b>	<b>Panel Discussion I: Living With COPD—Motivators and Barriers for Patients</b>	Facilitator: George I. Balch, Ph.D.
<b>11:15–11:30 a.m.</b>	Questions and Answers	Group
<b>11:30 a.m.–12:15 p.m.</b>	<b>Panel Discussion II: Treating COPD—Facilitators and Barriers for Health Professionals</b>	Facilitator: George I. Balch, Ph.D.
<b>12:15–12:30 p.m.</b>	Questions and Answers	Group
<b>12:30–1:30 p.m.</b>	LUNCH Sponsored by the Alpha-1 Foundation	

1:30–1:50 p.m.	<p><b>The Current Environment: Management and Treatment</b></p> <ul style="list-style-type: none"> <li>• What COPD disease management programs exist?</li> <li>• How effective and far-reaching are the programs?</li> <li>• What is the role of COPD guidelines in the clinical setting?</li> <li>• Are there educational materials?</li> <li>• Where are the gaps?</li> </ul>	Fernando J. Martinez, M.D., M.S.
1:50–2:00 p.m.	Questions and Answers	Group
2:00–2:20 p.m.	<p><b>The Current Environment: Early Detection and Diagnosis</b></p> <ul style="list-style-type: none"> <li>• What COPD screening programs exist?</li> <li>• What are the missions of these programs?</li> <li>• Whom do the programs target?</li> <li>• How effective and far-reaching are the programs?</li> <li>• Are there educational materials?</li> <li>• Where are the gaps?</li> </ul>	Dennis E. Doherty, M.D., F.C.C.P.
2:20–2:40 p.m.	Questions and Answers	Group
2:40–2:55 p.m.	BREAK	
2:55–3:15 p.m.	<p><b>The Role of Patient Advocacy Organizations in COPD Awareness and Education</b></p> <ul style="list-style-type: none"> <li>• What programs exist?</li> <li>• Whom do the programs target?</li> <li>• How effective/far-reaching are the programs?</li> <li>• Are there educational materials?</li> <li>• Where are the gaps?</li> </ul>	Pam DeNardo
3:15–3:25 p.m.	Questions and Answers	Group

<b>3:25–4:05 p.m.</b>	<b>Risk Factors for COPD Other Than Tobacco</b> <b>Tobacco as a Risk Factor for COPD</b>	A. Sonia Buist, M.D.  William Bailey, M.D.
	<ul style="list-style-type: none"> <li>• What programs exist for smoking cessation?</li> <li>• What are the missions of these programs?</li> <li>• Whom do the programs target?</li> <li>• How effective and far-reaching are the programs?</li> <li>• Are there educational materials?</li> <li>• Where are the gaps?</li> <li>• What are other preventive factors?</li> </ul>	
<b>4:05–4:15 p.m.</b>	Questions and Answers	
<b>4:15–4:30 p.m.</b>	<b>Brief Recap of Day 1; Focus for Day 2</b>	Homer A. Boushey, M.D., and John W. Walsh

**Thursday, September 23, 2004**

<b>8:30–9:00 a.m.</b>	<b>Continental Breakfast</b>	
<b>9:00–9:45 a.m.</b>	<b>Best Practices for Developing a National COPD Education Program</b>	George I. Balch, Ph.D.
<b>9:45–10:45 a.m.</b>	<b>Defining Needs and Opportunities</b>	Facilitator: George I. Balch, Ph.D.
	<ul style="list-style-type: none"> <li>• What are the educational gaps in COPD?</li> <li>• Where are the best opportunities for collaboration with NHLBI?</li> <li>• Lessons learned: What works and what doesn't work relative to the issues discussed on Day 1?</li> </ul>	
<b>10:45–11:00 a.m.</b>	BREAK	



11:00 a.m.–12:30 p.m.	<p><b>Small Group Breakout Sessions: Defining the Needs of Target Audiences and Making Recommendations for Awareness and Education Activities</b></p> <ul style="list-style-type: none"> <li>• Break into assigned groups: <ul style="list-style-type: none"> <li>• Group 1: Health care providers</li> <li>• Group 2: Those at risk for COPD; patients with early disease</li> <li>• Group 3: Patients with established disease; those with advanced disease</li> </ul> </li> <li>• Develop a list of priority areas to be addressed for the target audience</li> <li>• Create a list of recommendations for NHLBI education and awareness activities to address the identified priority areas</li> </ul>	Facilitated Session
12:30–1:30 p.m.	<p>LUNCH Sponsored by the COPD Foundation</p>	
1:30–2:15 p.m.	<p><b>Reports of Small Group Breakout Sessions</b></p> <ul style="list-style-type: none"> <li>• Presentation of main recommendations from each small group</li> </ul>	Group
2:15–2:30 p.m.	<p><b>Summary and Establishing Priorities</b></p>	Homer A. Boushey, M.D., and John W. Walsh
2:30–2:45 p.m.	<p><b>Closing Remarks</b></p>	James P. Kiley, Ph.D., Homer A. Boushey, M.D., John W. Walsh, and Gregory J. Morosco, Ph.D., M.P.H.

## Appendix B.

# Questions for Small Group Discussions

### Defining the Needs of Target Audiences and Making Recommendations for Awareness and Education Activities

#### 1. Who is the target audience?

- Who are the key segments?
- Prioritize segments.
- What do we know about each segment that seems most relevant to its COPD-related educational needs and behaviors?
- What educational information, knowledge, and messages are needed for the identified audience segments?
- What do they need to know, think, feel, or do?
- What messages would motivate or empower them to learn, understand, change their feelings and attitudes, or take the desired actions?

#### 2. What are the most critical COPD-related issues and needs facing this target audience?

- Review and discuss the key needs and issues raised during Day 1.
- What are the most promising opportunities, niches, and strategies for addressing these issues among this target audience?

#### 3. What types of materials, programs, tools, or other products will help address the priority areas among the target audience?

- Do effective programs, materials, and tools currently exist?
- Should or how can they be improved, adapted, adopted, or more widely used?
- What new materials, tools, products, and resources are needed?
- Who could best develop and disseminate them?

#### 4. What channels will best reach them?

- Potential partners: Who might help and how?
- Professional organizations
- Advocacy organizations
- Public health agencies
- Private-sector groups, media outlets, and other intermediaries

## For More Information

The NHLBI Health Information Center is a service of the National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health. The NHLBI Health Information Center provides information to health professionals, patients, and the public about the treatment, diagnosis, and prevention of heart, lung, and blood diseases and sleep disorders.

For more information, contact:  
NHLBI Health Information Center  
P.O. Box 30105  
Bethesda, MD 20824-0105  
Phone: 301-592-8573  
TTY: 240-629-3255  
Fax: 301-592-8563  
Web site: <http://www.nhlbi.nih.gov>

Discrimination Prohibited: Under provisions of applicable public laws enacted by Congress since 1964, no person in the United States shall, on the grounds of race, color, national origin, handicap, or age, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity (or, on the basis of sex, with respect to any education program or activity) receiving Federal financial assistance. In addition, Executive Order 11141 prohibits discrimination on the basis of age by contractors and subcontractors in the performance of Federal contracts, and Executive Order 11246 states that no federally funded contractor may discriminate against any employee or applicant for employment because of race, color, religion, sex, or national origin. Therefore, the National Heart, Lung, and Blood Institute must be operated in compliance with these laws and Executive Orders.



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
National Institutes of Health  
National Heart, Lung, and Blood Institute

Administrative Use Only  
December 2005