



Alpha-1 is a genetic condition, often called “Genetic COPD”. It’s the most common known genetic cause of COPD, yet less than 10 percent of the estimated 100,000 people with the most severe form of the condition have been correctly diagnosed. Most people with Alpha-1 (called Alphas) have lung symptoms, and often severe loss of lung function, for years before they are properly diagnosed – even though a simple and reliable blood test is available. The condition is treatable, but correct diagnosis is the first of many obstacles Alphas face.

The most common symptoms of Alpha-1 lung disease are shortness of breath, wheezing, chronic cough and sputum production, and recurring chest colds. The American Thoracic Society and the European Respiratory Society recommend Alpha-1 testing for anyone with COPD, bronchiectasis, incompletely reversible asthma and unexplained liver disease.

ALPHA ONE FOUNDATION

The Alpha-1 Foundation’s mission is increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency (or just Alpha-1).

A vital part of the Foundation’s mission has always been raising awareness of Alpha-1 – among the most common life-threatening genetic conditions, but still little known – among healthcare professionals, the general public and the makers of public policy in Washington.

None of those target groups takes more time and determined effort than public policy. And after years of work, 2008 was a landmark year for achievements in public policy that affect the Alpha-1 population.



Dennis Pollock, Alpha-1 Advocate, and Miriam O'Day, Public Policy Director

Some of those successes:

GENETIC DISCRIMINATION – Though lack of awareness remains the most important reason that the great majority of Alphas remain undiagnosed, there is another daunting issue: many people are afraid to be tested, because it could cost them health insurance or a job. The Genetic Information Nondiscrimination Act (GINA), which passed Congress overwhelmingly in 2008, makes it illegal for insurers and employers to discriminate based on genetic information.

“In gaining this landmark legislative victory, the role of the Alpha-1 community cannot be overemphasized,” says John Walsh, Alpha-1 Foundation President & CEO. “From day one, the dedication and perseverance of our Public Policy Director, Miriam O’Day, has helped make this — and other legislation — a reality.”

O’Day herself gives much of the credit to Oklahoma-based Alpha-1 advocate Dennis Pollock. “After GINA passed the House for the first time in its 14-year legislative history, it stalled in the Senate when

Oklahoma Sen. Tom Coburn put a hold on the bill,” O’Day says.

So Pollock flew to Washington in a fruitless attempt to persuade Sen. Coburn to release the bill for a Senate vote. Then Pollock mobilized the Alpha-1 community in Oklahoma, which flooded the senator’s office with phone calls. A months-long effort eventually succeeded when Pollock contacted Senate Majority Leader Harry

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Reid, “and asked him if he could push the legislation along,” said Pollock. “It was really a joint effort, and the whole Alpha-1 community should be proud. We got our point across.”

In September, the Foundation sponsored a workshop in Arlington, VA, to discuss the pros and cons of newborn screening for Alpha-1 after GINA takes effect. The expert panel at the workshop

recommended multiple pilot studies to study the issue.

AIRLINE OXYGEN -- Another victory that affects the lives of many Alphas was a ruling published in June by the US Department of Transportation that requires airlines to allow passengers to carry on board any of five approved portable oxygen concentrators.

The Airline Oxygen Council of America (AOCA) spearheaded the effort to ease access to medical oxygen for airline passengers. The AOCA website was funded by the Alpha-1 Foundation through a grant from the Ruderman Family Foundation, headed by Morton Ruderman, himself a lung-affected Alpha.

PULMONARY REHABILITATION has proven itself for many years to improve

quality of life for people with chronic lung conditions. Even though studies have shown that pulmonary rehab actually seems to more than pay for itself in lower health care costs and fewer hospitalizations, Medicare has never had consistent reimbursement.

“Pulmonary rehab reimbursement has been a challenge,” says Walsh. “Many rehab centers have closed down over the past few years because the Centers for Medicare & Medicaid Services (CMS) didn’t have consistent reimbursement policies in place, and many had to close because of cutbacks in reimbursement.”

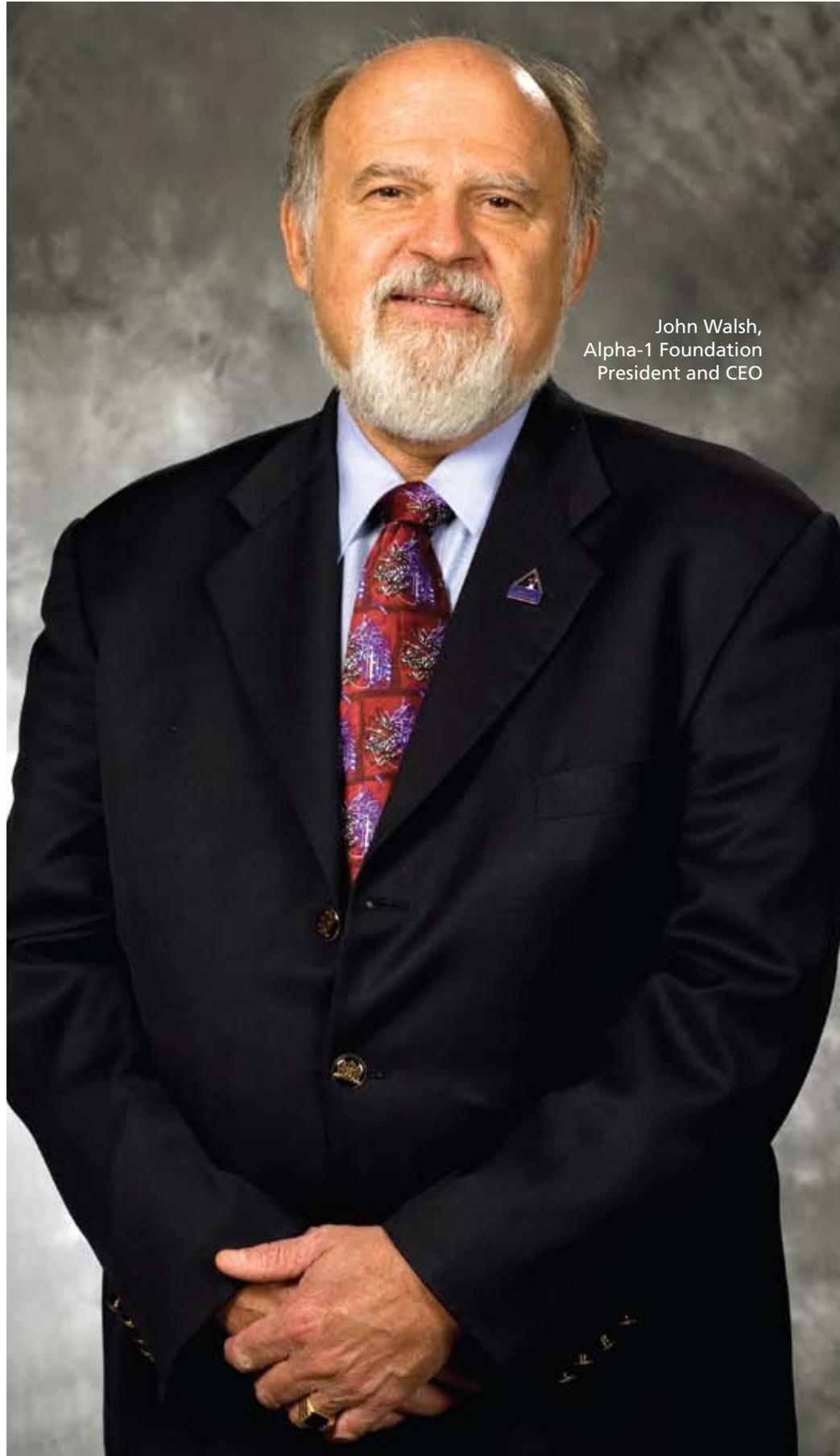
The Medicare package passed by Congress this year grants CMS the legislative authority to make pulmonary rehabilitation a permanent Medicare benefit. This victory followed many years of cooperative lobbying by the Alpha-1 Foundation, COPD Foundation, American Association for Respiratory Care and other professional societies and patient organizations.

“Kudos go to Ted and Grace Anne Dorney Koppel for their powerful COPD advocacy,” says Walsh. “Mrs. Koppel – who was diagnosed with COPD and is the national spokesperson for the NHLBI’s COPD: Learn More, Breathe Better campaign – was a very effective representative for us all.”

Pulmonary rehabilitation becomes a permanent Medicare benefit in January, 2010.

Of course, the Foundation could not have achieved these successes without the active cooperation of other patient advocacy organizations, government and industry partners.

“The Foundation couldn’t have achieved as much as it has without the help of partnerships such as we have with ASD Healthcare,” says John Walsh. “ASD has been a generous supporter of the Foundation’s Celebration of Life, our largest annual fundraising event, for the past three years.”



John Walsh,
Alpha-1 Foundation
President and CEO