

U.S. COPD Coalition Semi-Annual Business Meeting Official Meeting Minutes

May 20th, 2014

1:00pm-4:00pm

Omni San Diego Hotel; Gallery II

- I. Introduction
 - a. Take a look at our new logo, color, and website (uscopdcoalition.org)
 - b. **ACTION ITEM: register on the website; steps to register:**
 - i. Go to: uscopdcoalition.org
 - ii. Click on the “Members & Board” tab
 - iii. You will see a box on the right side of the page, click “Register”
 - iv. You will be sent to a different page; fill out the information and click “Register”
 - v. You will then have access to the full website and the forum feature
- II. Public Policy & Briefing Update
 - a. H.R. 460: Patients’ Access to Treatment Act
 - i. Overview: to amend title XXVII of the Public Health Service Act to limit co-payment, coinsurance, or other cost-sharing requirements applicable to prescription drugs in specialty drug tier to the dollar amount (or its equivalent) of such requirements applicable to prescription drugs in a non-preferred brand drug tier, and for other purposes
 - ii. Currently, 127 co-sponsors
 - iii. **ACTION ITEM: the COPD Foundation is looking to reach out to other organizations working on H.R. 460. Please contact Aimee Bulthuis, abulthuis@copdfoundation.org**
 - b. H.R. 1239: Accessing Medicare Therapies Act
 - i. Overview: to amend part D of title XVII of the Social Security Act to count the negotiated price of drugs provided free or at nominal charge under compassionate treatment programs towards incurred out-of-pocket costs
 - ii. Currently, 12 co-sponsors
 - c. H.R. 2619: Medicare Respiratory Therapist Access Act
 - i. Overview: to amend title XVIII of the Social Security Act to provide for Medicare coverage of pulmonary self-management education and training services furnished by a qualified respiratory therapists in a physician practice
 - ii. Currently, 31 co-sponsors
 - d. H.R. 1717: Medicare DMEPOS Market Pricing Program Act
 - i. Overview: to amend title XVIII of the Social Security Act to establish a market pricing program for durable medical equipment, prosthetics, orthotics, and supplies (DMEPOS) under part B of the Medicare program
 - ii. Currently, 178 co-sponsors
 - e. Midterm Elections and the Next Session
 - i. **ACTION ITEM: support Congressional COPD Caucus members in the upcoming election season**
 - 1. An election kit will be distributed to the full membership for this action
 - ii. The Public Policy Working Group will convene after the elections to complete an environmental scan; that information will be distributed to the full membership
 - 1. An agreement to allow industry partners to take part in this working group
 - f. E-Cigarette Legislation

- i. The U.S. COPD Coalition Board of Directors will create an optional sign on letter regarding it's' position on e-cigarettes
 - ii. Each organization who wishes to sign on to this letter will have its logo attached to the bottom of the letter
 - g. U.S. COPD Coalition Briefing
 - i. An overview of the event:
 - 1. Opening remarks, given by John Walsh
 - 2. COPD patient perspective, provided by Karen Deitemeyer
 - 3. Alpha-1 patient perspective, provided by Karen Erickson
 - 4. Data brief, given by Winston Liao
 - 5. Policy priorities, given by Miriam O'Day
 - 6. Closing/cocktail reception
 - ii. Successes:
 - 1. Gained three new Congressional Caucus Members
 - 2. Over fifty key attendees
 - 3. Overall, lots of positive feedback and interest
- III. Capitol Hill Updates
- a. COPD and Alpha-1 Foundations Capitol Hill Advocacy Day- May 6th, 2014
 - i. Focused on the following priorities:
 - 1. H.R. 460, H.R. 1239
 - ii. Seventeen COPD and Alpha-1 advocates, with senior leadership, flew in from across the nation and held over 60 meetings with their congressional members
 - iii. Gained Congressional COPD Caucus members; support for both pieces of legislation
 - b. AARC Capitol Hill Day- April 1st, 2014
 - i. Focused on the following priority:
 - 1. H.R. 2619
 - ii. Respiratory therapists from across the country had 325 meetings with their congressional members
 - iii. Resulted in eight new co-sponsors of H.R. 2619; created bi-partisan support
- IV. Centers for Disease Control and Prevention Update
- a. Please see the attached Centers for Disease Control and Prevention maps (also available on the USCC website), including:
 - i. Model-Based COPD Prevalence by County, United States, 2011
 - ii. Model-Based COPD Prevalence by Census Tract, United States 2011
 - iii. COPD Prevalence by Congressional District
- V. Strategic Plan Update
- a. Please see the attached strategic plan of the USCC (also available on the website)
 - b. Next steps: create actionable, measurable activities to correspond with the strategic plan
- VI. State Coalition Project
- a. A new project of the U.S. COPD Coalition based on the goals and objectives of the strategic plan
 - b. Overview:
 - i. An examination of our current eleven state and regional coalitions; many are active but are not active with the USCC
 - ii. An initial environmental scan was conducted which identified hundreds of potential organizations that could be part of the USCC nationwide
 - iii. What do current state and regional coalitions do? What is their potential value to the USCC?

1. Support and educate on state and regional policy
 2. Capitol awareness events
 3. State health improvement plans
 4. Pertinent resource sharing and promotion
 5. Other local/regional events
- c. First step: the Board of the Directors will complete a needs assessment of the current state and regional coalitions with the goal to engage them more and then seek expansion
- d. **ACTION ITEM: if you know of potential organizations that would like to join the U.S. COPD Coalition, please contact Rebecca Rudolph: rrudolph@uscopdcoalition.org**
- VII. Financial Update
- a. Provided by Sam Giordano on behalf of Barry Make, USCC Treasurer, who could not be present
 - b. Please see the presentation for the most updated financial information
 - c. Note: an extension has been filed for our 990 through August 2014; the Board of Directors is looking for a new auditor to decrease the overall cost of the process
- VIII. Communications Update
- a. You will begin receiving a quarterly newsletter from the U.S. COPD Coalition beginning in July
 - b. **ACTION ITEM: if your organization has any updated information, an upcoming event, policy information, or any information you would like to share in the newsletter, please send to Rebecca Rudolph at: rrudolph@uscopdcoalition.org by July 1st**
- IX. Election Overview
- a. Board of Director elections will take place prior to the next semi-annual business meeting
 - b. **ACTION ITEM: be on the lookout for the nominations and election process to begin mid-summer**
- X. New Business/Closing
- a. Next Semi-Annual Business Meeting date: Tuesday, October 28th, 2014 in Austin, Texas; in conjunction with the American College of Chest Physicians CHEST Conference