COPD Foundation's Pulmonary Education Program (PEP)

Program Report
October 2012 - December 2015



COPD Foundation Pulmonary Education Program (PEP) 2012-2015

EXECUTIVE SUMMARY

Pulmonary rehabilitation is an essential component of successful medical therapy for individuals with COPD. Rehabilitation programs improve quality of life for patients and reduce health care utilization. The initial challenge is to enroll patients in these programs. The larger challenge is to KEEP patients engaged long-term and motivate them to permanently change their behavior.

That's the goal of the COPD Foundation's Pulmonary Education Program (PEP).

PEP is designed to help select pulmonary rehabilitation centers nationwide offer an exceptional experience to individuals with COPD by:

- Providing disease-specific patient education materials to patients, free of charge
- Supporting staff members at PEP Centers across the country with ongoing training and professional development
- Providing personalized health management strategies and long-term support within the COPD community through the PEP On Track with COPD Ongoing Health Management program
- Providing enrolled individuals, their caregivers and their healthcare providers with a variety of COPD educational resources, free of charge

PEP was conceived following a COPD Foundation focus group of pulmonary rehabilitation healthcare professionals.

Since its inception in 2012, PEP has enrolled hundreds of pulmonary rehabilitation centers and thousands of patients across the country. The original PEP goal of enrolling 250 pulmonary rehab centers was accomplished ahead of schedule and by the end of 2014, 256 pulmonary rehabilitation centers from 44 states had enrolled in the PEP program. In addition, 7,636 "Welcome Kits" and 6,201 "Graduation Kits" had been distributed to PEP pulmonary rehabilitation centers. At the end of 2014, PEP Coordinators reported that 3,468 patients had graduated from PEP pulmonary rehabilitation programs.

PEP On Track

An integral part of PEP is the *On Track with COPD Ongoing Health Management* program, which provides patients with personalized education and social support via telephone following graduation from pulmonary rehab. PEP *On Track* encourges individuals to embrace self-management of their disease and remain engaged with the COPD community, long term.

PEP On Track is optional, confidential and effective.

The PEP *On Track* program begins where traditional pulmonary rehabilitation leaves off —by offering a unique approach to helping patients develop long-term, personalized health management skills. The optional PEP *On Track* program does this with a series of 24 monthly phone calls from highly trained COPD peer coaches. The core tools employed by the PEP *On Track* program are education, motivation and community engagement—all implemented as part of a carefully designed curriculum.

PEP: A Powerful Tool

Through PEP, the COPD Foundation has multiple affiliates across the country to promote its core message: "To prevent and cure COPD and to improve the lives of all people affected by COPD." With its accredited educational webinars and community workshops, PEP offers a powerful tool for increasing awareness of this mission within the COPD community and beyond.

The **Pulmonary Education Program** is off to a fast start - showing solid results and rapid expansion. The demand for high-quality patient educational materials and professional, long-term support continues to grow. Our goal in 2016 and beyond is to meet that demand with our innovative PEP and PEP *On Track* programs.

This is a unique program. In traditional pulmonary rehabilitation programs people finish the initial program and drop off a cliff. We're different. Patients get free educational materials and after they finish pulmonary rehab, they sign up for our On Track program to receive one-on-one support to ensure long-term behavior modification. That's unique.

- John Walsh
President and Co-Founder, COPD Foundation

THE COPD FOUNDATION'S PULMONARY EDUCATION PROGRAM—PEP

Pulmonary Rehabilitation: A Win, Win

When individuals with COPD participate in pulmonary rehabilitation (PR), their overall health-related quality of life (HRQoL) improves dramatically—with reduced dyspnea (difficulty breathing), improved exercise capacity, increased knowledge of effective management of COPD and a better emotional outlook on their condition. Pulmonary rehabilitation also reduces COPD exacerbations, hospitalizations and the overall cost of medical care for these patients. Clearly, participants enrolled in pulmonary rehab programs work hard to improve their quality of life—despite COPD. Unfortunately, reduced reimbursement rates, a limit in lifetime Phase II sessions and no Medicare reimbursement for Pulmonary Rehab Phase III maintenance leave many pulmonary rehab programs struggling to survive.

Enter the COPD Foundation's *Pulmonary Education Program* (PEP). PEP is a groundbreaking program designed to support select pulmonary rehabilitation centers across the country with up-to-date, disease-specific patient education materials. PEP also offers the *On Track with COPD Ongoing Health Management* program, in which a team of highly trained COPD-peer associates makes monthly telephone calls to graduates of PEP pulmonary rehab programs. This highly structured, yet friendly program consists of 24 phone calls over a period of about two years. It is designed to review the pulmonary rehab COPD curriculum, provide encouragement and emotional support and build a long-term connection to the COPD community. In short, the PEP *On Track with COPD Ongoing Health Management* program picks up where traditional PR programs leave off. For patients who graduate from a pulmonary rehabilitation program that offers continuing Phase III maintenance, PEP *On Track* is still valuable. Not all graduates are able to continue in Phase III, and for those who do, PEP *On Track* offers an additional layer of ongoing education, support and engagement.

Individuals with physician-diagnosed COPD who are formally referred to a pulmonary rehabilitation program are qualified to be PEP patients. These individuals are: 1) affected by COPD to the extent that they are compromised in performing activities of daily living, 2) willing to learn about COPD and improved lung health and 3) ready to change their behavior to attain a better quality of life. PEP is designed to reach them with written educational materials and provide the guidance of a trusted healthcare professional to reinforce the education and opportunities offered by the COPD Foundation.

PEP Fills a Gap

The Pulmonary Education Program was conceived following a COPD Foundation focus group of pulmonary rehabilitation healthcare professionals at the 2010 American Association of Respiratory Care Summer Forum. Feedback from these experts made it clear that although the short-term effects of pulmonary rehabilitation are firmly established in multiple outcome areas, its long-term effectiveness (i.e., after ~2 years) is disappointing. The panel felt that two factors play a pivotal role in this loss of effectiveness: exacerbations of COPD following rehabilitation and a gradual decrease in adherence to the post-rehabilitation exercise prescription [19]. The experts agreed that pulmonary rehabilitation should include strategies to promote long-term adherence [1].

In October 2012, PEP was rolled out. Based on studies of pulmonary rehabilitation and patient engagement, PEP was designed to increase participation in patient support groups, provide community education workshops and offer ongoing, long-term telephone support through the COPD Foundation's Information Line peer health coaches. Program organizers envisioned that these elements would improve compliance with physicians' recommendations, promote long-term adherence with medication therapies and improve participation in exercise and nutritional programs. Research indicates that these practices lead to relief in symptoms [2–4, 6, 8–13], improvement in exercise tolerance [4–11, 13–15], improvement in health status [4, 6, 9, 13, 16, 17] and prevention of exacerbations and complications [10, 18]. The initial goal of PEP was to promote long-term adherence to optimal therapy for individuals with COPD after they graduate from pulmonary rehabilitation.

Objectives

Since its inception, PEP has evolved into a comprehensive health management program designed to improve health outcomes for individuals participating in pulmonary rehabilitation by:

- Providing free, disease-specific patient education materials for use during the Phase II rehabilitation program and for long-term use following graduation.
- Supporting staff members at pulmonary rehabilitation centers across the country with ongoing training and educational webinars. By focusing on the latest developments in COPD (diagnosis, treatment, management, research and policy issues), professional development is promoted, thus raising the level of knowledge and skills for the pulmonary rehabilitation practitioner. Updates on PEP program essentials and training sessions help PEP Coordinators and staff get the most out of PEP, for their patients, their organization and themselves.
- Connecting patients via the PEP On Track with COPD Ongoing Health Management program
 with peer health coaches after they leave a rehabilitation program, providing personalized health
 management strategies, ongoing support and long-term social engagement with the COPD
 community.
- Providing enrolled individuals with COPD, their caregivers and their healthcare providers with access to an extensive catalog of free COPD educational resources and direct telephone access to the COPD Foundation's Information Line Associates.
- Offering COPD Community Education Workshops for local COPD communities (patients, family members, healthcare providers and pulmonary rehab center staff).
 - I can't say enough about PEP and how our patients have gained so much from all the resources. Many thanks to the COPD Foundation for making it possible for us to receive these materials—it's really helped our pulmonary rehab staff and our patients.
 - Linda Pinn, MSN, RN, RCP
 Illinois Valley Community Hospital, Peru, IL
 PEP# 193-IL

Components of the Pulmonary Education Program

To qualify as a **PEP Center**, a facility must be a hospital or physician office that is a Medicare-qualified Phase II outpatient pulmonary rehabilitation program or a Comprehensive Outpatient Rehabilitation Facility (CORF). The pulmonary rehabilitation center must provide comprehensive disease management education as part of the program. The PEP Coordinator at each PEP Center signs a formal agreement with the COPD Foundation stating they will provide select COPD Foundation educational materials (see below) to physician-referred individuals with COPD. PEP Coordinators are also required to complete a quarterly online survey with feedback about how their program is using PEP. Each PEP Center is issued a unique code containing a three-digit serial number and the state abbreviation.

PEP Educational Materials

PEP educational materials include a **Patient Welcome Kit** and a **Patient Graduation Kit** that promote effective health management for people with COPD who enroll in a PEP pulmonary rehabilitation program. The PEP Center also receives a **Pulmonary Rehabilitation Staff Box** (see appendix for full fetails of this Box), which contains additional resources to educate staff and enhance patient education sessions. One critical tool in the Staff Box is the **Big Fat Reference Guide** (**BFRG**), a 400-page, comprehensive COPD resource.



- The Big Fat Reference Guide is a wonderful and helpful reference for our staff. They use it regularly as a resource.
 - Anne Gavic, MPA, RCEP
 Northwest Community Hospital, Arlington Heights, IL
 PEP# 229-IL

PEP Participant Welcome Kit

- PEP logo string bag
- Set of Slim Skinny Reference Guide® (SSRG) booklets, covering the 10 most salient topics on COPD and written at a 6-8th grade literacy level; fun to read and easy to understand
- Slim Skinny Reference Guide® (SSRG), "COPD in the Hospital and the Transition Back to Home"
- "Patient Welcome Letter," including a unique patient ID number to protect patient privacy
- "Start Your Engines" checklist
- Patient folder with COPD Foundation information and opportunities
- "Report Early Signs of Exacerbations" card

PEP Patient Graduation Kit

Designed for COPD patients who complete a PEP pulmonary rehabilitation program, Graduation Kits feature materials related to long-term disease self-management, including:

- Certificate of graduation
- Optimal Care for COPD Including Getting the Most Out of Your Medications booklet
- C.O.P.D Information Line contact information
- Sit and Be Fit Exercise DVD—COPD Workout
- A Patient's Guide to Aerosol Drug Delivery
- Operation 435 and other COPD Foundation volunteer opportunities
- COPD Registry or Patient-Powered Research Network information
- "Live Your Life with COPD 52 Weeks of Health, Happiness and Hope" book

Note: PEP Welcome and Graduation Kit educational materials are also used as the foundation for review in the PEP *On Track with COPD Ongoing Health Management* program curriculum, thus providing continuity and minimizing costs.

A **PEP Coordinator** is the healthcare professional at the PEP Pulmonary Rehabilitation Center who is the direct point of contact for the COPD Foundation's **PEP Managers**. PEP Coordinators are responsible for reordering PEP kits when stock is low and for completing a quarterly survey. PEP Managers use this survey to continually improve the PEP program. PEP Managers also maintain an ongoing performance log for each PEP Center. If a PEP Coordinator fails to complete two consecutive quarterly surveys or comply with other PEP standards, that program will be at risk for disqualification.

A **PEP Participant** is an individual, diagnosed with COPD, who enrolls in a PEP Center Pulmonary Rehabilitation program. Once enrolled, each participant receives a PEP Welcome Kit. Upon graduation, each participant receives a PEP Graduation Kit.

PEP Participant Identifying Information

To protect the privacy of each PEP participant and comply with <u>Health Insurance Portability and Accountability Act</u> (HIPPA) regulations, no patient identifying information is shared between PEP Center Coordinators and PEP Managers/the COPD Foundation. If a patient pre-enrolls in the optional PEP *On Track with COPD Ongoing Health Management* program, he or she is identified only by the unique patient ID number that is assigned via the PEP Welcome Kit. PEP Coordinators and PEP Managers refer to a specific patient only by the assigned ID number from the Welcome Kit. For example, "PEP Participant 001-IN, 058" is the 58th participant to join PEP Center 001-IN, which is Union Hospital—Terre Haute Pulmonary Rehabilitation in Indiana.

HOW PEP WORKS

PEP as a Partner

Through PEP, the COPD Foundation provides easy-to-read and easy-to-understand COPD educational materials to PEP Pulmonary Rehabilitation programs. The PEP Center uses the materials in its education program and encourages patients to review them on their own. PEP Centers also provide exercise conditioning and emotional support—all are part of their comprehensive pulmonary rehabilitation program.

Upon graduation, PEP participants are encouraged to maintain the gains they made in pulmonary rehab by formally enrolling in the PEP *On Track with COPD Ongoing Health Management* program. PEP *On Track* offers a seamless transition to life after pulmonary rehab and includes ongoing education, support, encouragement and accountability for optimal long-term health.

PEP Provides Two-way Communication

Through PEP, the COPD Foundation has multiple affiliates across the country (256 PEP Centers in 44 states) to promote its core message: "to prevent and cure COPD and to improve the lives of all people affected by COPD." The COPD Foundation provides educational materials and ongoing support to patients and healthcare professionals. PEP is a powerful tool for increasing awareness about these services within the COPD community.

PEP Center personnel also inform PEP participants about other important COPD Foundation initiatives. For example, PEP participants are encouraged to enroll in the Patient-Powered Research Network (PPRN), PEer-Led O2 Infoline for patients and Caregivers (PELICAN), advocacy activities and other special programs.

Measuring Success of PEP Centers

PEP Managers and the COPD Foundation value the overall activity level, initiative, innovation and responsiveness of individual PEP Centers. PEP Managers record the number of patients pre-enrolled in the PEP On Track with COPD Ongoing Health Management program, track the number of orders for Welcome

- The PEP Materials we send home with the patients really help reinforce what we teach in class.
 - Denise Holt, CRT
 St. Joseph Hospital, Bangor, ME
 PEP# 123-ME

Kits and Graduation Kits and note participation in quarterly webinars and mandatory surveys. PEP Managers also recognize top performers in COPD Foundation literature and at COPD Foundation events.

PEP Managers Track Distribution of Education Materials

PEP Coordinators request Welcome Kits and Graduation Kits based on current inventory at the PEP Center and the number of patients expected to use those training materials. PEP Managers order the materials, which are shipped through the fulfillment center, and then PEP Coordinators distribute them directly to patients. PEP Managers track distribution of these materials to patients via the quarterly reports.

Training PEP Coordinators

Since the inception of the program, PEP Managers have ensured that individual PEP Center Coordinators, staff members and patients benefit from the program as much possible. To that end, in addition to evaluating program data, PEP Managers carefully analyze comments from PEP Coordinators in quarterly feedback surveys. This candid input has resulted in ongoing quality improvement and positive changes to PEP.

For example, in early surveys, PEP Coordinators indicated that they needed clarification on how PEP educational materials and processes could be most effectively used as part of the PEP *On Track with COPD Ongoing Health Management* program. PEP Managers listened. Small-group training sessions started in March 2014, and more than 250 PEP Coordinators and PEP Center staff members from 230 different PEP Centers have received this special training—resulting in a significant increase (more than 100 percent) in referrals to the PEP *On Track* program.

Group conference-call training also resulted in PEP Coordinators placing additional reorders of Welcome Kits and Graduation Kits and increased sign-up for the online catalogue and more effective use of existing educational materials.

Impact of PEP Training on Use of Patient Educational Materials (direct use of materials in teaching and informing PEP participants as reported by PEP Coordinators)

	BEFORE	AFTER	INCREASE OF
"Impact of Smoking" graph	35%	47%	12%
Registry Kit	55%	62%	7%
Information Line cards	34%	43%	9%
Sign-up for online catalogue by PEP Coordinators	75%	84%	9%

From October 2012 through January 2014 (16 months), a total of 359 patients, representing 75 different PEP Centers, pre-enrolled in PEP *On Track*. In the eleven months from February 2014 through December 2014, an additional 501 patients, representing a total of 132 different PEP Centers, pre-enrolled in PEP *On Track*. This 157 percent increase in PEP *On Track* pre-enrollment was achieved in less than a year

and represents a 76 percent increase in participation from PEP Centers successfully encouraging patients to pre-enroll.

In addition to helping PEP
Coordinators use PEP materials
more effectively, PEP Managers
found an unexpected benefit from the

- The conference training calls have helped us utilize our PEP program more effectively.
 - Aimee Cottrell, RRT, AE-C Union Hospital Terre Haute, Terre Haute, IN PEP# 001-IN

group conference-call training. The personal touch of small-group interactions helped often-isolated PEP Coordinators find support from peers, a fresh perspective on PEP educational materials and a greater appreciation for the COPD Foundation.

Accredited Webinars for PEP Center Staff

PEP Managers host four educational webinars each year for PEP Coordinators and PEP Center staff members. Each webinar features a specific COPD-related topic and provides participants (PEP Coordinators, PEP Center staff members and C.O.P.D Information Line Associates) the opportunity to earn continuing education credit. These live webinars are archived and available as an ongoing resource for new PEP Center staff members and Information Line Associates. Quarterly webinars also

The webinars have helped to educate our staff so we can deliver better service, use better treatment methods, techniques and ideas thus improving our patient outcomes and better customer experience.

- Chris Brehm, PT, DPT, OCS

Lifeline Therapy-McMurray, McMurray, PA
PEP# 010-PA

feature PEP administrative updates. Each live webinar attracts an average of 100 participants.

PEP WEBINARS

2012 - Pulmonary Education Program Introduction. Jane Martin, BA, CRT, LRT. Live attendance, 43

2013 - Total yearly live attendance, 181. Total yearly viewers of recorded attendance, 149

February 13, 2013: What PEP Coordinators Should Know about Spirometry. Scott Cerreta, BS, RRT. Live attendance, 22; Viewed recording, 40

May 14, 2013: *Pulmonary Rehab Billing and Reimbursement Update.*Teena Culhane, BHK, RRT 066-MI. Live attendance, 56; Viewed recording, 48

August 13, 2013: *Pulmonary Rehabilitation Registry.*Chris Garvey, FNP, MSN, MPA, FAACVPR 126-CA. Live attendance, 47; Viewed recording, 36

November 12, 2013: On Track Success Stories.

Robert Rosneck, MA, RRT, CEP 064-OH, and Cathy Schmidt, RRT 079-MI. Live attendance, 56; Viewed recording, 25

2014 - Total yearly live attendance, 349. Total yearly viewers of recorded webinar, 74

February 11, 2014: New Medications for COPD.

Scott Cerreta, BS, RRT. Live attendance, 96; Viewed recording, 29

May 13, 2014: Challenges in Oxygenation of the COPD Patient.

Connie Paladenech, RRT, RCP 141-NC. Live attendance, 101; Viewed recording, 25

August 12, 2014: AACVPR Certification: Moving Towards Program Excellence & Excellent Outcomes. Kim Beyer, BS, FAACVPR. Live attendance, 71; Viewed recording, 12

November 11, 2014: Increasing Referrals to your Pulmonary Rehabilitation Program.

Valerie McLeod, RRT 036-Ml. Live attendance, 81; Viewed recording, 8

COPD Community Education Workshops

PEP Managers and the COPD Foundation provide support for PEP Centers interested in hosting a COPD educational workshop in their community. As part of the COPD Community Education Workshop series, the COPD Foundation enlists expert speakers to lead an informative and engaging discussion on COPD-related topics. Community Education Workshops are staged in regions of the country with a high prevalence of COPD and interest from a host PEP Center.

COPD Community Education Workshop, Denver, Colorado, September 3, 2014

A COPD Community Education Workshop held in Denver attracted more than 150 participants—individuals with COPD, interested family members, caregivers and healthcare professionals. Four nearby PEP Centers, three non-PEP medical facilities and over forty students from local respiratory-care colleges collaborated with the COPD Foundation to stage a successful workshop. Topics included:

- COPD 101 with 3-D Interactive Tutorial: Why You're Short of Breath
- · Pulmonary Rehabilitation: Use It or Lose It
- How Harmonica Playing Helps if You Have COPD (including live performance and demonstration)
- The Power of the Patient in Finding Cures, Introducing the Patient-Powered Research Network (PPRN)

Onsite spirometry testing was provided to 31 participants and Alpha-1 Antitrypsin Deficiency screening was provided to 25 participants. Sixteen exhibitors participated, providing information on resources, products and services to improve the health of people living with COPD. Please see the appendix for a complete listing of other COPD Community Education Workshops. See the appendix for a complete listing of all PEP

Workshops.

- Having these kits keeps our cost down and the patient satisfaction up, which are both great ways to make sure our administration keeps our program alive in the setting of healthcare cost cutting.
 - Linda Breen, MS

 Pocono Medical Center, East Stroudsburg, PA

 PEP# 232-PA

Positive Feedback from PEP Coordinators

PEP Coordinators report that PEP educational materials provide a high-quality, consistent message that enhances their program and enables them to focus on other budget priorities (purchasing equipment, improving

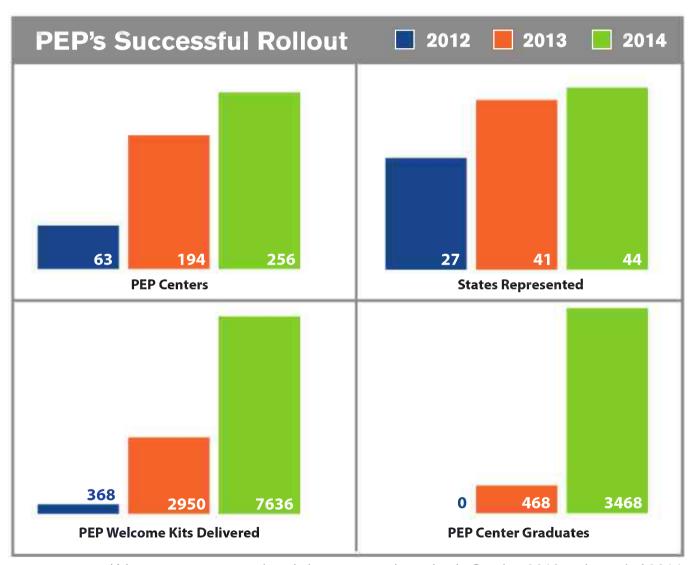
processes and staff wages). For some pulmonary rehabilitation programs, PEP makes the difference, ensuring survival of the program itself in the often-uncertain health education environment.

PEP Wrap Up

When the PEP program began in October of 2012, the plan was to enroll 250 pulmonary rehab centers across the country by the end of 2014. This goal was accomplished eight months ahead of schedule. By the end of 2014, 256 pulmonary rehabilitation centers from 44 states had enrolled in the PEP program.

In addition, 7,636 participant Welcome Kits and 6,201 Graduation Kits were distributed to PEP pulmonary rehabilitation centers. At the end of 2014, PEP Coordinators reported that 3,468 patients officially graduated from PEP pulmonary rehabilitation programs.

The first three years of PEP were dedicated to building the program, creating the PEP *On Track* curriculum and recruiting PEP Centers. Once a PEP Center is enrolled, it takes about three months to get up to speed and efficiently enroll patients using the PEP Kits. The original goal of recruiting 250 PEP Centers was achieved in April 2014 and, as the following graph indicates, with all centers up to speed, there was a sharp increase in PEP Kits delivered to the PEP Centers by the end 2014.



Values represent a grand total since program inception in October 2012 to the end of 2014.

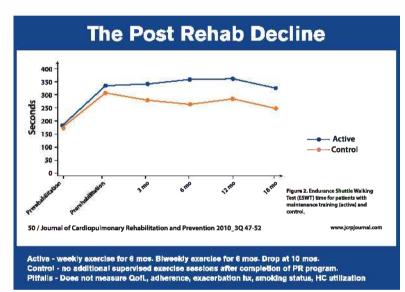
Results from calendar year 2015 will be released in early 2016.

- These materials help keep the patients motivated in their own care. Our PEP patients have stated that they were given a wealth of information about their disease, its control and treatment. They also say they have fewer admissions to the hospital with rehab and PEP. \$\frac{17}{2}\$
 - Donna Hopkinson, BS, CRT 163-MA Sturdy Memorial Hospital, Attelboro, MA

The PEP On Track with COPD Ongoing Health Management Program

Decline in Effective Self-management Following Non-PEP Pulmonary Rehabilitation

The PEP On Track with COPD Ongoing Health Management program is a critical extension of the



Pulmonary Education Program. When people with COPD complete a non-PEP pulmonary rehabilitation program, they often fall back into frequent exacerbations and declining health. Even for pulmonary rehab programs with Phase III maintenance available, not all patients are able to participate, putting them at risk for exacerbations.

In a randomized controlled study by Ringbaeck [20]; they measured patient performance following a community-based pulmonary rehabilitation program based on exercise tolerance over six months. Clearly,

there is a dramatic fall off when the formal pulmonary rehab program ends. Note that this study measured only exercise tolerance. It fails to address other facets of pulmonary rehab, including quality of life (QoL), smoking status, knowledge of health management, attitude toward personal health and accomplishment of personal goals.

PEP On Track Is Unique

The PEP On Track with COPD Ongoing Health Management program begins where traditional pulmonary rehabilitation ends—with a unique approach to developing long-term, personalized health management skills. The optional PEP On Track involves a series of 24 monthly phone calls to patients from highly trained COPD peer coaches. The core tools employed by the PEP On Track

PEP provides patients with an additional, unique support system. Often patients fall back into bad habits after they finish pulmonary rehab. PEP On Track has truly helped many patients keep their focus.

- Bob Rosneck, MS, RRT, CEP University Hospitals Orange Village, OH PEP# 064-OH

program are education, motivation and community engagement—all implemented as part of a carefully designed curriculum.

C.O.P.D. Information Line Associates Training

"Call Our Patients Direct" (C.O.P.D.)
Information Line Associates are highly trained peer health coaches that include both patients as well as caregivers who initiate
PEP On Track outbound calls to patients enrolled in the program.

Information Line Associates complete 80+ hours of training that include:

- Job skills assessment and extensive "Agent 101"
 Customer Service training
- Active Listening
- Motivational Interviewing & Goal Setting
- Program specific training (including PEP)
- HIPPA Certification
- Ongoing Call Monitoring, Quality
 Assurance and weekly educational training

How PEP On Track Works

When people with COPD begin Phase II participation in a PEP Pulmonary Rehab program, pulmonary rehab staff encourage them to contact the Call Our Patients Direct (C.O.P.D.) Information Line to learn about the PEP On Track with COPD Ongoing Health Management program. After learning about PEP On Track, patients may accept or decline pre-enrollment. Patients are eligible to pre-enroll any time during their Phase II Pulmonary Rehab experience up to two weeks following graduation from pulmonary rehabilitation.

When patients complete pulmonary rehabilitation at a PEP Center, they receive a Graduation Kit filled with valuable COPD resource materials. C.O.P.D Information Line

- Pulmonary rehabilitation is a spectacularly effective therapy for COPD. It's greatest challenge, however, is to maintain benefits in its participants after the program ends. PEP On Track addresses this and keeps rehabilitation graduates engaged with the COPD Foundation. Great program!
 - Richard Casaburi, MD, PhD

 Los Angeles Biomedical Research Institute at Harbor

 UCLA Medical Center

Associates (see sidebar) contact pre-enrolled

patients by phone within a few days of their graduation. Following this introductory Call #1, patients are considered formally enrolled in the PEP On Track with COPD Ongoing Health Management program.

The PEP On Track with COPD Ongoing Health Management program averages 70 new patient preenrollments every month, and the goal is to rformally enroll and retain as many participants as possible for

- Connects many, even those who are almost homebound, to a larger network, especially through the On Track program. My patients who use On Track really love it. They feel like someone cares about them and their disease.
 - Chaffee Tommarello, BSRT, RRT, LRTR, AE-C Cabin Creek Health Center, Dawes, WV PEP# 121-WV

all of the 24 monthly sessions. Some patients who are pre-enrolled in PEP *On Track* are still actively working with their pulmonary rehab program and are not yet eligible to start PEP *On Track*. Also, many participants who pre-enroll in the PEP *On Track* program fail to complete the Phase II pulmonary rehabilitation program (nationally, only 60 percent of patients complete pulmonary rehab). As a result, although 860 patients pre-enrolled in PEP *On Track*, only 369 patients formally enrolled in the PEP *On Track with COPD Health Management* program.

PEP On Track Curriculum

The formal curriculum for the PEP *On Track with COPD Ongoing Health Management* program was launched in March of 2014. This curriculum, developed in collaboration with pulmonary rehabilitation educators around the country, consists of 17 specific COPD-related topics, each essential for individuals with COPD to help maintain physical and emotional health.

Each call starts with the assigned topic(s) and ends with five quick check-up items and a series of engagement questions. The average call takes about 20 minutes, and the goal is simple: to connect with patients, one-on-one, keeping them engaged in ongoing education and social support by walking through specific COPD-related topics, answering questions and encouraging them to stay *On Track*. The curriculum is well-designed. A series of response-dependent items provide additional teaching assignments only when needed. Therefore, every patient has a customized educational experience tailored to their specific needs.

With ongoing feedback from patients, pulmonary rehab staff and Information Line Associates, the PEP *On Track* curriculum will evolve over time, but the objective will remain the same: to help patients gradually change their behavior by imparting crucial information about effective long-term COPD self-management skills.

The PEP *On Track* curriculum is highly structured and sophisticated in its implementation, providing a comprehensive, long-term pulmonary rehabilitation follow-up program for PEP facilities, free of charge.

The PEP *On Track* curriculum involves 24 individual calls, covering 17 specific COPD topics (see sidebar).

PEP On Track Topics

- Recognizing & Treating AECOPD
- Exercise
- Medications
- Smoking Cessation
- Breathing Techniques
- Understanding COPD
- Oxygen
- Energy Conservation & Work Simplification
- Nutrition
- Airway Clearance
- Healthcare Professional Appointments
- Traveling with COPD
- **Emotions**
- End-of-life Issues
- Co-morbidities
- ► Hospitalization & the Transition to Home
- Relationships

For the first three calls, the C.O.P.D Information Line Associate and the patient tackle only one topic at a time (e.g., Recognizing and Treating Acute Exacerbations of COPD). As the program unfolds, two topics might be addressed in a single call (e.g., Understanding COPD and Oxygen Therapy; Nutrition and Relationships).

PEP On Track participants are welcome to call the C.O.P.D. Information Line anytime, as often as they want. Time is available at the end of each PEP On Track call for the patient to ask additional, unrelated questions.

The purpose of each monthly call is to help pulmonary rehab graduates maintain the gains they made and avoid declining health by receiving personalized coaching and assigned homework. These discussions are drawn directly from the educational materials provided in the PEP Welcome Kit and Graduation Kit.



The order of topics —and the content structure over time—has been carefully designed. During the program, every topic is repeated at least twice and some especially critical topics are discussed three times (e.g., Goals, Exacerbations, Exercise, Medications and Smoking Cessation). A few topics will "fall off" the curriculum when the information is no longer germane for an individual with COPD. For example, if the patient does not wear oxygen, that topic will no longer be addressed as part of the curriculum in upcoming calls.

In some cases, the entire curriculum can be completed in 24 months, but often because of travel, hospitalization, special events, and so forth, patients require more time to complete the program. Regardless of any gap in the schedule, the Information Line Associate resumes the PEP *On Track* program with the next call in the prescribed curriculum sequence.

PEP On Track is optional, confidential and effective.

Knowledge and Confidence Items Measure Progress

Participants' confidence and knowledge are assessed using questions or statements referred to collectively as items. These items measure overall understanding of the material and evaluate the patient's knowledge and confidence about using the information to facilitate long-term COPD health management. Each item is scored on a scale of 1 to 5 points, where 5 points is the most favorable response. Using this system, PEP Managers can track individual patient changes in knowledge, confidence, health maintenance and engagement in the COPD community over the course of the PEP *On Track* program. Only aggregate data is reported to protect individual patient responses. Results reveal that the PEP *On Track* program is very effective.

The PEP *On Track* curriculum automatically guides the Information Line Associate through the process of asking questions, listening to responses, determining knowledge and confidence, reviewing resources with the patients during the call and encouraging further review by the patient after the call.

Knowledge Items

Within the curriculum for each educational topic, some PEP *On Track* items are designed to measure a patient's knowledge or actions related to a specific behavior. For example:

I am taking all my medications as prescribed, even when I'm breathing well.

Strongly disagree Disagree I don't know Agree Strongly agree

I do some form of endurance exercise (walking, biking, stepper, rowing) at least three times a week.

Strongly disagree Disagree I don't know Agree Strongly agree

Confidence Items

The other type of item in the curriculum for each educational topic measures confidence. Confidence is an important factor in any educational program. Prior to enrolling in PEP *On Track*, participants often report a low level of confidence in some topic areas. PEP Managers expect to see increased confidence levels on repeated items over time, thus highlighting a marked improvement. For example:

I use a Spacer when using my MDIs (metered dose inhalers—inhalers that spray a mist).

Not at all confident Somewhat confident I don't know Confident Very confident

I use the pursed-lips breathing technique when I exercise.

Not at all confident Somewhat confident I don't know Confident Very confident

Confidence vs. Knowledge

Responses to confidence items and related knowledge items do not always correlate. For example, a patient may know that it is important to take all medications as prescribed, but that same patient may reveal a low level of confidence that they are, in fact, taking all their medications as prescribed. If Information Line

Associates find gaps, they will work with the patient to help bring confidence in line with knowledge.

Coaching vs. Homework Assignments

During the course of each PEP *On Track* call, Information Line Associates cover items that are selected for either live coaching or homework assignments. Coaching is required for items that are considered most important, and these items are discussed right away. Homework is assigned for less

44 Our patients who use the On Track program love it—that psychological boost/encouragement is something I cannot give them. 77

- Mary Beth Winney, RN Carilion Franklin Memorial Hospital, Rocky Mount, VA UCLA Medical Center PEP #225-VA

critical items that may require more lengthy study; these are assigned to the patient for reading on their own. In addition, coaching and homework assignments are marked as either mandatory (required for all patients) or response dependent. The nimble PEP *On Track* curriculum seamlessly guides the Information Line Associate through the call process in a way that ensures a customized approach for each participant.

Mandatory vs. Response-dependent Content

Mandatory content is information considered critical to understanding COPD health management. This content is covered regardless of an individual's response to the knowledge or confidence item.

Response-dependent content is triggered based on the response score. Any response less than 5 points will trigger response-dependent coaching or a homework assignment.

The objective is to measure a change in behavior over time for both mandatory content and response-dependent content. Even a four on a scale of five leaves room for improvement. PEP Managers will measure changes in scores for identical questions from year one and year two of the PEP *On Track* program. Results from year two are expected to be available in late 2015 or early 2016.

Five "Quick Check-Up" Items Are Repeated Every Month

Start of Official Curriculum on 3/29/14 Cumulative Data to 12/31/2014

Percent of participants answering "strongly agree" or "agree"										
		Call 1	Call 2	Call 3	Call 4	Call 5				
1	I am taking all my medications as prescribed, even when I'm breathing well.	98%	98%	98%	99%	96%				
2	I do some form of endurance exercise (walking, biking, stepper, rowing) at least three times a week.	86%	90%	79%	84%	85%				
3	I understand and use the pursed lips breathing technique whatever I exert.	96%	96%	96%	96%	94%				
4	I have not smoked since graduation from pulmonary rehab.	93%	96%	99%	95%	98%				

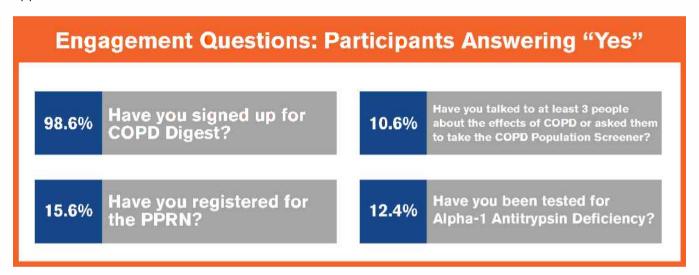
Percent of participants answering "yes"									
5	Since graduation from Pulmonary Rehab, have you:	Call 1	Call 2	Call 3	Call 4	Call 5			
5a	Gone to the doctor's office for breathing problems?	20%	26%	24%	31%	35%			
5b	Gone to the ER for breathing problems?	5%	9%	9%	13%	12%			
5c	Stayed overnight in the hospital for breathing problems?	5%	11%	9%	11%	13%			
54	Had any breathing problems that required you to seek medical help?	18%	28%	22%	30%	23%			

Patients' outcomes are tracked and overall behavior change is monitored.

It's clear that patients who enroll in the PEP *On Track with COPD Ongoing Health Management* program continue to learn and maintain healthy behaviors long after their participation in a pulmonary rehabilitation program is over. For a complete listing of the On Track curriculum items assessed for Monthly Calls 1-5, refer to the Appendix.

Engagement Questions Evaluate a Patient's Involvement and Interest in the COPD Community

At the end of each monthly call, patients are asked to respond to a revolving series of engagement questions. As patients respond positively to questions, those questions "fall off" the list and are not asked again. Answers to these questions demonstrate how individuals are or are not becoming more engaged in the COPD community. Some people accomplish these tasks quickly and others need more time. Each engagement question is asked in a predetermined order and frequency. These engagement items correspond to the Start Your Engines Checklist which is included in the Patient Welcome kit. See the appendix for full details.



Patient Feedback for PEP On Track with COPD:

During each monthly call, C.O.P.D Information Line Associates encourage patients to provide feedback about the *On Track* program. Comments have been overwhelmingly positive.

The PEP *On Track* process is fluid and strategic. The strategy is to build sustainability into the program by helping PEP *On Track* participants become savvy ambassadors for the COPD Foundation and the PEP program itself—sharing a core message of effective

Abby H.: "PEP On Track is fabulous. I love the way you keep in touch with me."

Jeffery L.: "I look forward to the PEP On Track calls."

self-management and self-reliance with other members of the COPD community.

COPD360social - A tool to encourage PEP On Track participants to become involved in the COPD Community by:

- Sharing their story and finding other individuals like them
- Joining the COPD Patient-Powered Research Network
 - Being tested for Alpha-1
 - **Actively promoting PEP to others living with COPD**
 - Subscribing to the COPD Foundation's publications and online newsletter
 - **Encouraging people at-risk to participate in the COPD Population Risk Screener**
- **PEP 2015—Accomplishments** Launched in 2012, the Pulmonary Education Program is off to a fast start, showing solid results and rapid expansion. The demand for high-quality patient educational materials and professional, long-term support continues to grow. Our goal is to meet that demand with our flexible and innovative PEP and PEP *On Track* programs. 2015 accomplishments include:
 - Recruit seven new PEP Centers from these underrepresented states:
 Delaware, Kansas, Nebraska, Nevada, North Dakota, Utah, and Washington.
 - Served over 4,000 new PEP participants and enrolled over 300 additional PEP On Track participants.
 - Expanded training and accredited educational webinars for PEP Coordinators and PEP Center staff.
 - Enhanced patient access to COPD360social.

- I got good news from my CMO that our COPD readmissions for last quarter were at zero! He felt that it was in large part because of our rehab program. That couldn't have happened without our partnership with the COPD foundation. Thanks so much for helping our program be successful.
 - Ron Cothran, BS, RRT, CPFT St. Mary's Corwin Medical Center, Pueblo, CO PEP# 186-CO
- Increased percentage of PEP participants who enroll in the PEP On Track with COPD Ongoing
 Health Management program.
- Increased participation in the Patient-Powered Research Network (PPRN).

Challenges Ahead

There are many challenges ahead. Over 110 pulmonary rehabilitation programs are currently on a waiting list to join the program. The initial projection of 2,500 patients per year was eclipsed and more than 5,000 projected to join in 2016. PEP Managers expect to enroll 500 new PEP *On Track* participants, with 75 percent of those individuals staying engaged with the COPD Foundation.

Unfortunately, PEP resources are limited. To continue to meet the challenge, PEP must evolve and new funders must be secured in order to continue offering PEP. New support for PEP will permit the COPD

- Our goal for 2016 is to expand our support for PR programs nationally, improve patients' ability to self-manage their COPD and recruit hundreds of new patients into the unique, long-term support network of PEP On Track. Our ultimate goal is to help these folks improve their quality of life for years to come.
 - John Walsh
 President and Co-Founder
 COPD Foundation

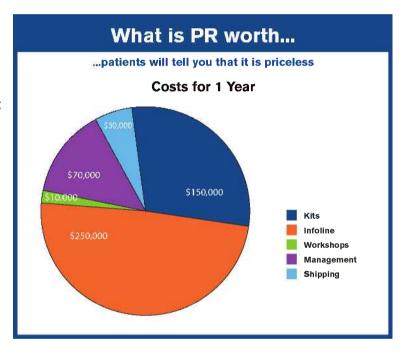
PEP is a groundbreaking program that:

- Provides patients in pulmonary rehabilitation centers across the county with up-to-date, disease-specific patient education materials at the start of their PR program
- Supports pulmonary rehab staff throughout the PR program
- Implements the post-graduation On Track with COPD Ongoing Health Management program
- Our patients really appreciate the opportunity that we have gotten through the COPD Foundation! Their eyes light up when they get their diploma and graduation packet with DVD and book!
 - Aleshia Bloker, RN, BSN
 Allen Memorial Hospital, Waterloo, IA
 PEP# 249-IA

Foundation to enroll new pulmonary rehabilitation centers from the waiting list and expand web-based resources to make it easier for PEP Centers and patients to access the materials they need to improve their quality of life and health management skills.

PEP and Pulmonary Rehabilitation—A Seamless, Long-term Approach

Participants enrolled in pulmonary rehabilitation work hard to improve their quality of life—despite having COPD, a complex, difficult-to-manage disease.



This seamless, long-term approach to pulmonary rehabilitation helps PR graduates stay on track during their challenging journey with COPD. The components of the PEP program combine to help patients achieve their rehabilitation goals, maintain the best quality of life possible and develop a long-term connection to the COPD community.

GLOSSARY

PEP Center

A Medicare Phase II-qualified pulmonary rehabilitation program that signs an agreement to formally enroll into PEP and is assigned a program number.

PEP Center Staff

Healthcare professionals at a PEP Center who make up the multidisciplinary team of professionals at a pulmonary rehab facility.

PEP Coordinator

Primary point of contact who communicates with COPD Foundation staff.

PEP Managers

The COPD Foundation staff responsible for the Pulmonary Education Program.

PEP On Track with COPD program

This is an optional ongoing health-management program for patients who graduate from a PEP Center. This program features 24 monthly calls led by a peer health coach.

PEP On Track Pre-Enrollment

Patients may pre-enroll in PEP On Track from the time they join a PEP program until two weeks after they graduate from pulmonary rehab.

PEP On Track Formal Enrollment

Patients are formally enrolled into the PEP On Track program after graduation from a participating PEP program and completing PEP On Track call number one.

PEP On Track Participant

A patient who is eligible and formally enrolled in On Track.

PEP Participant

A person with COPD who enrolls into a qualified PEP Pulmonary Rehab program.

Pulmonary Rehabilitation Phase I

The period of time between the initial physician referral and the start of regularly scheduled exercise and education sessions.

Pulmonary Rehabilitation Phase II

Regularly scheduled monitored exercise and education sessions run by credentialed healthcare professionals two to three times a week; covered by health insurance and/or Medicare for qualified patients.

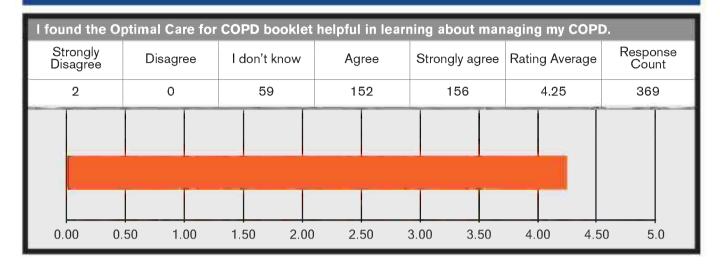
Pulmonary Rehabilitation Phase III (Maintenance)

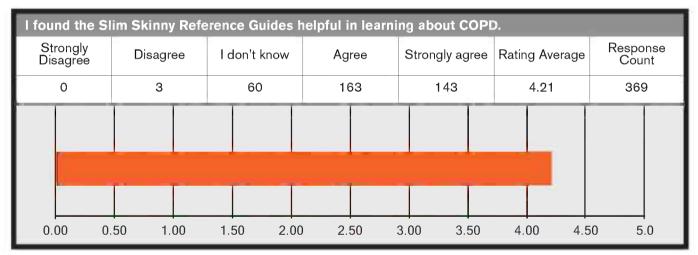
Continuing exercise following pulmonary rehab graduation; less structure and monitoring, self-pay.

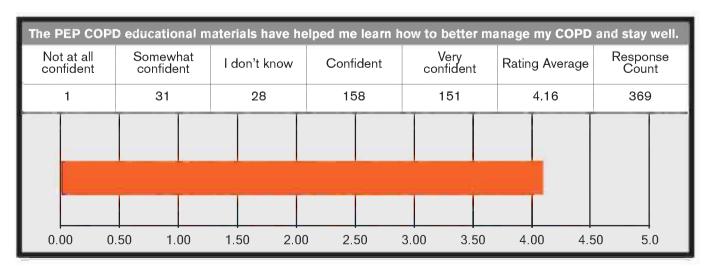
APPENDIX

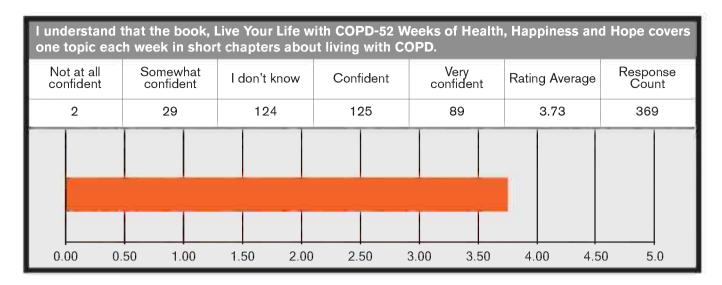
Results reported in the Appendix are from program inception, October 2012 to December 31, 2014. Results from calendar year 2015 will be released in early 2016.

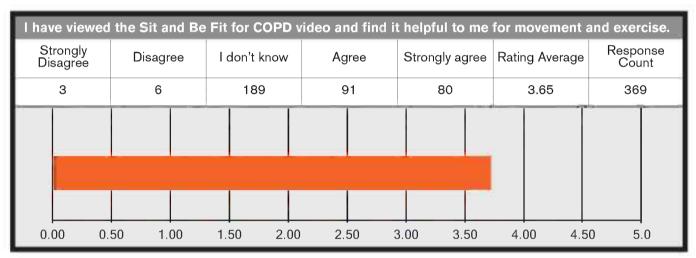
PEP On Track Call #1 - Welcome & Goals

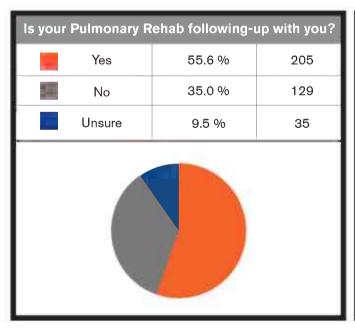


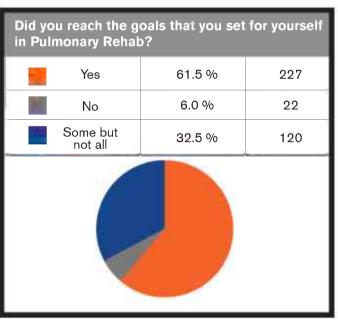




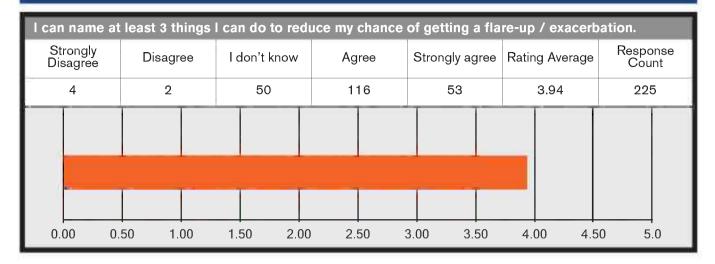




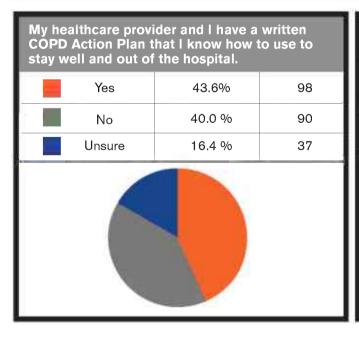


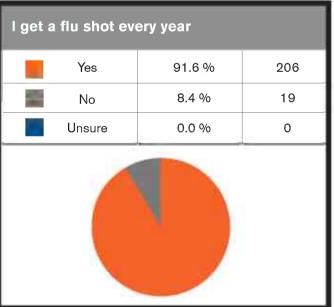


PEP On Track Call #2 - Avoiding Exacerbations (Flare-Ups)

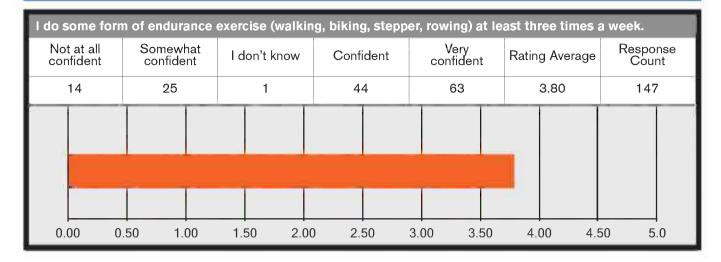


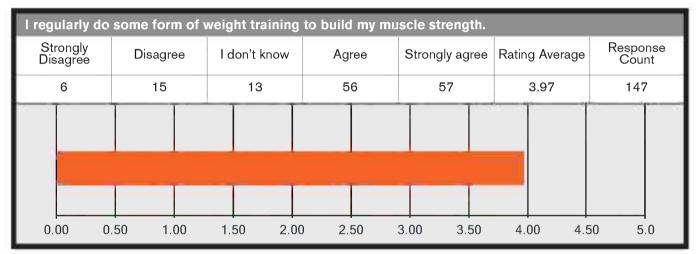
I can name	e 3 dange	er signs th	at requires	me to ca	all 911 for i	mmediate	e help.			
Not at al confiden	l So	Somewhat confident		now	Confident		ery fident	Rating Average		Response Count
7		36	32		81	1	69	3.75		225
	T				T					
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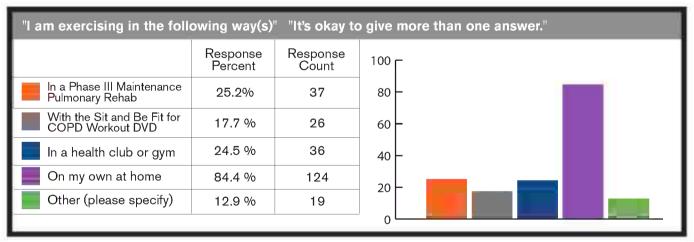




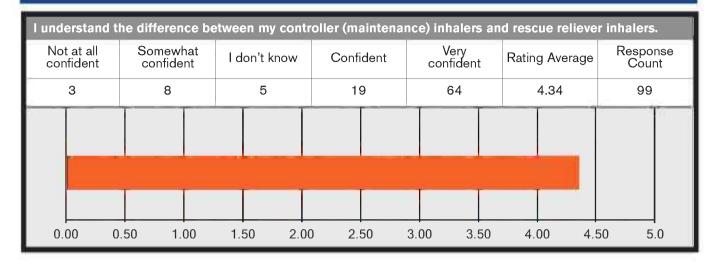
PEP On Track Call #3 - Exercise

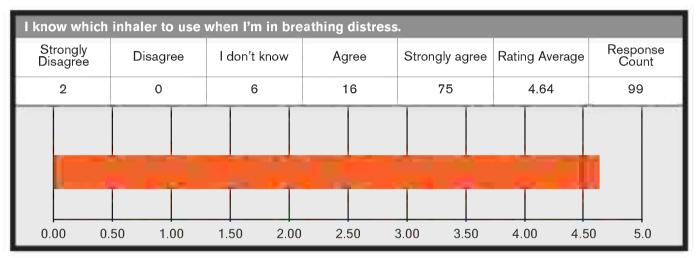


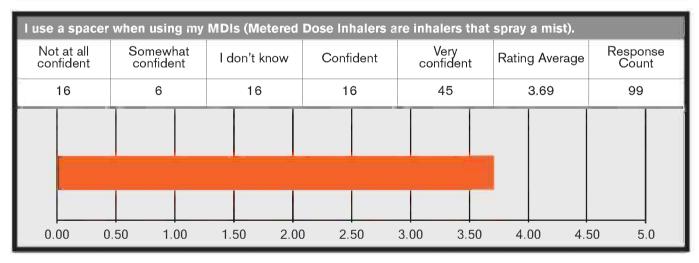




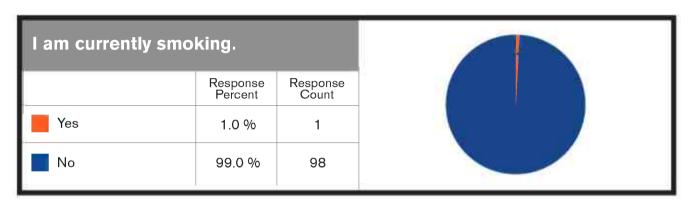
PEP On Track Call #4 - Medications and Smoking

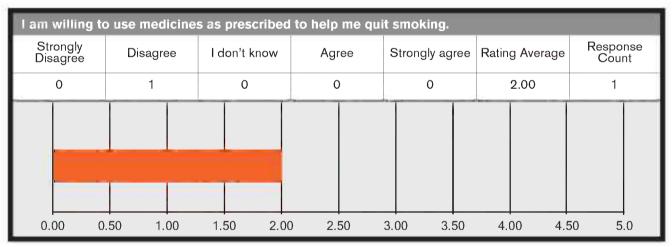


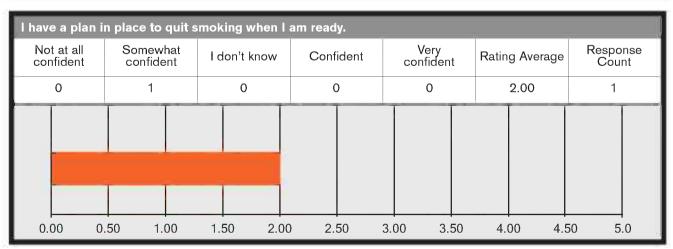




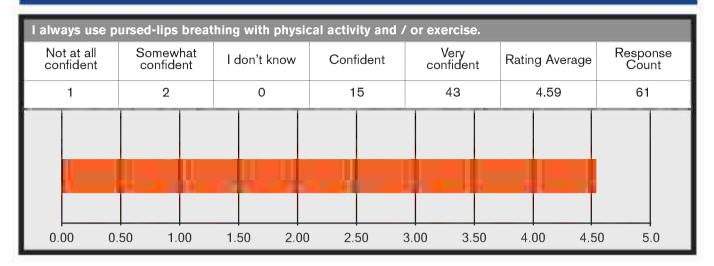
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1		2	26		30		40	4.07		99		
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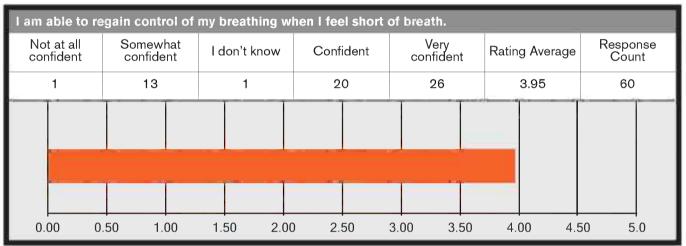


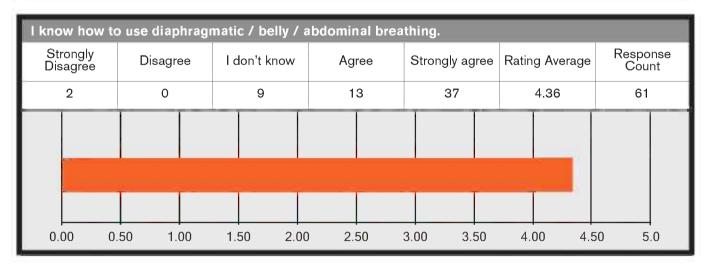




PEP On Track Call #5 - Breathing Techniques







PEP Pulmonary Rehab Staff Box for Pulmonary Rehab Centers

Packets for pulmonary rehabilitation staff include:

- · Overview of COPD Foundation, its programs and mission
- COPD Foundation Educational materials
 - Big Fat Reference Guide (BFRG), hard-copy book, the most comprehensive educational material currently available to individuals with COPD (available in 10 languages)
 - The 1,2,3s of COPD
- AARC HCP Aerosol Guide
- Information on testing for Alpha-1, the genetic form of COPD
- COPD Advocacy information
- · Support group instruction kit
- Subscriptions to the COPD Digest and Lung Health Professional Magazine
- Sit and Be Fit Exercise DVD COPD Workout
- Fifty-pack of COPD Pocket Consultant Guide 4x6 pocket cards

COPD Community Education Workshops hosted since program inception





Start Your Engines Checklist

As an individual with COPD there's a lot you can do to help yourself, your family and others with COPD. As you gain strength, we encourage you to look carefully at each item on this checklist. Ask yourself, "Is this something I can do to help myself, my family or others Learn More and Live Healthy with COPD?" See what you can do, and then check-off the appropriate boxes before you graduate to the Winner's Circle.

Here's what you can do:

Call the C.O.P.D. (Call Our Patients Direct) Information Line 1-866-316-COPD (2673) and tell them you're in a PEP Pulmonary Rehab program. You will be asked to provide the name of your Rehab Center and your On Track ID number. As a member of PEP, you qualify to join the On Track with COPD program, in which you'll benefit from ongoing support and information on what you can do to stay healthy, active and independent with COPD. Furthermore, a COPD Associate can assist you completing most boxes on this checklist. Call them at 1-866-316-COPD (2673).

- Take a look at these PEP materials: the Big Fat Reference Guide® (BFRG) download from our website and the Slim Skinny Reference Guides® (SSRGs). You are sure to find lots of information on how to tune-up your health with COPD.
- Sign up for the COPD Digest by calling a COPD Associate at 1-866-316-COPD.
- Join the COPD Patient Powered Research Network (PPRN) it's easy! The COPD PPRN connects researchers with patients in order for researchers to learn and understand more about COPD, to advance treatment options and ultimately to find a cure. COPD PPRN information is included in your PEP welcome materials.
- Get tested for Alpha-1, the genetically inherited form of COPD by asking your doctor or pulmonary rehab center for a test. If the test is not available in your area, please ask a COPD Associate at 1-866-316-COPD.
- 🔲 Take action! Become a COPD Advocate. Call and speak with a COPD Associate at 1-866-316-COPD.
- Visit the COPD 360social at www.copdfoundation.org and tell us how you are doing in
- Encourage at least three people you know (family counts!) to complete the 5-question COPD population screener to check their risk for COPD. Get screened online at www.copdfoundation.org. Click on the "Risk Screener" on the home page.
- Visit the Coaches Corner at www.copdfoundation.org/COPDYou/ CoachesCorner.aspx and submit your question to "Ask Our Experts!"
- Donate to the COPD Foundation to help support COPD programs and research. You may donate by mail or by calling 1-866-316-COPD. A contribution card has been included in your PEP welcome materials.

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