# **‡** AMERICAN LUNG ASSOCIATION

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National President and CEO Harold P. Wimmer December 21, 2016

Andrew Slavitt
Acting Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Re: CMS-2016-26515

**Dear Acting Administrator Slavitt:** 

The American Lung Association appreciates the opportunity to submit comments to the Centers for Medicare & Medicaid Services (CMS) regarding the final rule on the Medicare Hospital Outpatient Prospective Payment System (OPPS) and the Medicare Ambulatory Surgical Center (ASC) payment system. This set of comments from the Lung Association addresses reimbursement changes for pulmonary rehabilitation.

The American Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through education, advocacy and research. The organization represents lung disease patients, their families, loved ones and caregivers.

The American Lung Association works to better the lives of those with chronic lung disease including chronic obstructive pulmonary disease (COPD). COPD has been increasing in prevalence and is the third leading cause of death in the United States. During 2007-2010, around 8.5 million adults had been diagnosed with COPD. However, this may represent underdiagnoses of the true burden as more than 18 million had evidence of impaired lung function. When detected and treated early, COPD can be controlled.

Pulmonary rehabilitation is an important component in COPD management and treatment.<sup>5</sup> Comprehensive pulmonary rehabilitation is critical for improving lung function, reducing

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55 West Wacker Drive, Suite 1150 | Chicago, IL 60601 Ph: 312-801-7630 F: 202-452-1805 info@Lung.org symptom severity and improving quality of life through better physical and emotional health. It is clinically effective and a vital path toward strengthening the patient's self-management of their health condition through patient education led by an interdisciplinary team of allied health professionals. The American Lung Association has included patient stories that emphasize the significant positive impact that pulmonary rehabilitation has had on their quality of life (see appendix).

The American Lung Association is concerned that the proposed changes to pulmonary rehabilitation payments may widen the existing gaps in access to pulmonary rehabilitation programs, including access in rural areas. The Lung Association strongly urges CMS to recognize that the current payment changes recommended for pulmonary rehabilitation may impact access to this life-saving treatment for millions of patients and requests CMS to ensure that patient access will not be jeopardized.

The American Lung Association respectfully appreciates the opportunity to submit our comments for the final rule on the OPPS and ACS payment systems. The Lung Association strongly urges CMS to address our concerns by ensuring that appropriate measures will be enforced to safeguard patient access to quality care and treatment.

Sincerely,

Harold P. Wimmer

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National President and CEO

<sup>&</sup>lt;sup>1</sup> Centers for Disease Control and Prevention. National Center for Health Statistics. National Vital Statistics Report. Deaths: Final Data for 2013 Detailed Tables. December 2014; 64(02). No Title.

<sup>&</sup>lt;sup>2</sup> Centers for Disease Control and Prevention. National Health Interview Survey, 2007-2010 and 2014. Analysis by the American Lung Association Epidemiology and Statistics Unit using SPSS Software.

<sup>&</sup>lt;sup>3</sup> Tilert T, Dillon C, Paulose-Ram R, et al. Estimating the U.S. Prevalence of Chronic Obstructive Pulmonary Disease Using Pre- and Post-Bronchodilator Spirometry: The National Health and Nutrition Examination Survey (NHANES) 2007–2010. *Respiratory Research*. 2013; 14(1):103.

<sup>&</sup>lt;sup>4</sup> United States Census Bureau. Population Estimates, 2007-2010.

<sup>&</sup>lt;sup>5</sup> McCarthy B, Casey D, Devane D, Murphy K, Murphy E, Lacasse Y. Pulmonary rehabilitation for chronic obstructive pulmonary disease. *The Cochrane database of systematic reviews*. 2015; 2.

# **Appendix**

The American Lung Association reached out to its community, including patients, health care practitioners and Lung Association staff, and asked how pulmonary rehabilitation has positively impacted the quality of their lives or the lives of their patients. Below are the comments the Lung Association received. They have not been edited.

#### Dale M.

I have been going to the SVMC Pulmonary Rehab program since July of 2014 and have benefitted greatly from the exercise program and the helpful information that is provided to us in dealing with COPD. Although COPD has yet to be cured, the Pulmonary Rehab program has instilled in me the knowledge and confidence that I can live a normal and comfortable life. With the popularity of the program there certainly is a need for the program to continue as the folks that are directly involved in running the program are doing an exceptional job. I hope that my information has been helpful in determining the continuation of the program.

#### Daniel S.

I started out on Medicare as primary insurance when my pulmonologist ordered liquid oxygen for me to use. Since that time my wife retired and my primary insurance changed to Aetna (an Advanced Medicare Type C Plan) with Medicare Type B becoming secondary. Since Apria has been changing out as many of their liquid O2 customers as possible to compresser O2 as an economy move, they have approached me via multiple phone calls stating they were changing me over to compessor O2 since Medicare is no longer my primary. I have refused, as I've looked up on the Medicare.com site under DME, under O2 supplier, that the only way for a DME O2 supplier to stop providing the doctor prescribed type of O2 within a five year period, was if the entire company went out of business ... but that as long as the company was still doing business across state lines it may Not require any changes in the doctor's prescribed O2 on it's own. I complained to Medicare and after a long while received a phone call stating that as an Atena customer I was no longer covered under Medicare regulations. But as I read the Medicare regs it states that Type C Medicare is an alternative to Type B Medicare that may be chosen. And Atena is a Type C Medicare plan. I called up Aetna and they concurred ... "don't let them {Apria} change your doctor's orders". Now Apria says they since they own their own liquid oxygen equipment that thay are free to confiscate it at their discretion. I told them "no, you are not allowed on my property", but only allowed in my driveway to refill my reservoirs for two more years to fulfill the original contract. My doctor agrees, rather than have me file an ethical complaint against his state medical license. And now I intend to file an ethical complaint against the Respiratory Therapist under the employ of Apria who has called me most recently. Am I fighting a losing battle, in your opinion?

#### Gail H.

My name is Gail Harris and for several years I have worked assisting patients with lung disease. I have seen first hand the horrible affects of not being able to breath as well as the benefits of Pulmonary Rehabilitation programs that assist with dyspnea and improve with the activities of daily living. Several patients have communicated their appreciation and need for Pulmonary Rehab. Below are quotes from three people that participated in pulmonary rehab. "Since I have participated in these rehabilitation sessions I have noticed that I am better able to deal with simple tasks like walking. I depend upon Pulmonary Rehab to ensure that my health will not continue to deteriorate." "Pulmonary Rehab has helped me to learn how to maintain and control my breathing problems. Since attending the sessions I have had less visits to the emergency room." I have learned more from Pulmonary Rehab than I did from any of my clinic appointments. I believe that Pulmonary Rehab should be mandatory for anyone living with lung disease. Being in the program helped to decrease my fears and anxieties and taught me how to cope with my emphysema." My outcomes indicate that patients are able to walk further with less shortness of breath. Their muscles become stronger, they eat healthier and overall have a better quality of life. Pulmonary Rehab programs provide patient education and give the patients the tools that they need to better take care of themselves while providing a safe atmosphere to exercise, socialize and get the medical resources that they need to live a better life. These programs are vital. If taken away it would leave a negative impact on many lives.

#### Kirsten D.

I have been in a pulmonary rehabilitation program, offered by St. Luke's Hospital, two times. It has been of benefit to me both physically and psychologically. The program has provided direction that counteracts the languishing and despair that can occur when faced with an incurable disease. The physical benefits help in just feeling better. Any program, without a caring and expert staff is, of course, of very little meaning. A program can have an excellent facility, equipment, and a well-designed program, but without those caring staff, would be of little help. I have been blessed to be with staff that is caring, encouraging, understanding, and invested in my outcomes.

## Betty.

I attended a Pulmonary Rehab progam in Feb and March of this year. I suffer from both COPD and pulmonary arterial hypertension and the program has been a God send for me. The quality of my life has been enhanced in so many ways. More energy, less shortness of breath, less fatigue. It has given me hope that I didnt' feel before. PLEASE DO NOT CONSIDER CUTTING FUNDS FOR THIS LIFE GIVING TREATMENT THAT CAN HELP SO MANY WITH THIS DISEASE.

#### Anonymous.

Pulmonary Rehabilitation restored my confidence. I have "always" been an exerciser. I have had a chronic cough since 1985 and had seen several doctors over the course of the years, but after a couple chest xrays, no further treatment was offered. I quit smoking in 1996 and vigorously expanded my exercise routine to counter any adverse effects

smoking may have had on my lungs. I was easily walking a 12 minute mile (30 to 45 min. per day) and doing strength/conditioning exercises. Fast forward to 2015 and while in my doctor's office for routine check up had a coughing fit. She decided to administer spirometry test. I could not move the plastic thingy. So, after a pft with fev1 of 25%, I was referred to a pulmonologist. I had been noticing shortness of breath and had slowed down considerably, I believe it is called "compensating." The pulmonologist was surprised at my vigor, given the numbers, but did not prescribe PR until I requested it. I was afraid of the truth and my denial convinced me that I was just out of condition and exercise would prove the doctors wrong. I entered PR with a fear of the shortness of breath exercise/exertion caused. It felt like my life was eroding. PR taught me pursed lip breathing, that breathing hard is different from not being able to breathe, how to pace myself, and gave me confidence to pursue exercise on my own again and I purchased a pulse oximeter. Interacting with other people with lung disease was invaluable. There were some formal information sessions on diet, use of inhalers, etc..., but I learned just as much from other patients' experiences with whom I could identify. I still avoid situations in which my shortness of breath will become obvious to "healthy" people. I walk alone, or exercise at home (I couldn't talk to anyone and exercise at the same time anyway). In PR we had the freedom to be as we were without fear of disgrace or judgment. It was a liberating experience.

## Anonymous.

In their 40's one half of a couple went to cardiac rehab, the other pulmonary rehab. They have matching T-shirts they wear over regular clothing when they walk together inside a store or outside on the street...the front says, Walking does my heart good (with a picture of a heart), the back says I walk with (arrow) because I can, with a picture of lungs. The cardiac patient has the heart on the front, the pulmonary patient, the lungs. He /she/they built their dream home set back 1/4 mile from the mailbox. Drove the golf cart to get mail every day till rehab program. Now, fair or foul weather, off on foot for the mail, adding a bit more distance, satisfaction, accomplishment and pride each day. A proud veteran wanted a flagpole into which he could slip his flag, rather than raise it. He wanted one he could reach, with his reduced stature due to back injuries, place in and take out as he did not want to install a light (what should be done if a flag is left out at night). He designed, made, installed the pole (which swivels so the flag never gets tangled) and every morning he puts it out, every evening he retires it. Neighbors have watched him salute it. He told his plans to all in rehab and they have a picture of him and the flagpole in their center. Alone in senior housing conveniently built near a W-M but with no car, too far...until rehab. Bought a shopping cart, walks to W-M, and walks home. Independence, empowerment, role model. Now an active volunteer with the Christmas Santa program, getting there by foot or bicycle. Grandparent assuming the role of parent needed the stamina to accomplish this monumental task on a daily basis. Motivation for rehab. Infant in tow, regular sessions, completed program. Now has established a local grandparent raising grandchildren support group and they all meet for regular walks, talks on topics including health and fitness. Everyone saw the individual who was coming for maintenance work but who was failing to see any improvement while others were adding minutes each session. It took the constant assurance of each new patient that the example of diligence to maintenance was an example for each, for all. We watch, we learn, we're grateful. Whether it is individual motivation or peer encouragement (we have seen, heard, the stories, read the stories in posts) no one except someone who understands the fear, anxiety, sadness of our inability to breathe with ease, can appreciate the difference a rehab experience can have.

## Anonymous.

PR has been invaluable for me both physically and mentally. I live alone and I work full time. I have to get things done myself. Things I struggled with before are more manageable now; exercise makes navigating life a little bit easier. I am not so wibbly wobbly. I am much stronger now, I take strong solid steps, I am more sure of myself. Of course I still get sob and there are times when I have to sit and rest but I do think I recover faster and I definitely have more energy and less fear. In Dec 2015 I started PR. I only did one month, the co-pay was prohibitive for me. The one month of PR was enough to get me going. I bought an oximeter and on my last day of rehab I joined the wellness center across the street. I continued the same program I had been doing in PR but I did it more often and more of it. With the help of one of the trainers, I slowly started doing some strengthening and some things to help my flexibility and balance. In July 2016 I did a level 3 (?) pulmonary exercise program. This was very different, this was full on strength training. I exercised with a physiologist and a RT standing right there helping me the whole time. It was amazing. It was the best thing for me physically and mentally. I walked out of there with a customized strengthening program along with some knowledge of how to progress. Oddly enough when I am at the gym working out I don't feel like I have a chronic illness, I am not a stage anything, I am just me and I feel good. All of this started one year ago at PR on the treadmill for 10 mins at a speed 1.8. So yes I found PR helpful.

## California: Frances H.

While in pulmonary rehabilitation at UCSF, I improved in several areas.

-Endurance- I increased my treadmill time from 2-6 minutes and also was able to walk 6 minutes without stopping by the end on the program. -Learning-the most important improvement I made was understanding how to manage my breathing when my oxygen was low. I became an expert at pursed lip breathing and inhale 2, exhale 4, both of which I have used when I was short of breath. -Exercise I learned the importance of aerobic exercise and especially loved the Nu Step. My only regret is that Nu Steps aren't available in many gyms, but they are in maintenance facilities which I also use. Emotionally-Working together with other patients on a goal of improving health, supported by a team of professionals was a very positive, life affirming experience for me.

## Colorado: Louise N.

Pulmonary Rehab has many benefits for patients with chronic pulmonary disease. I was a part of the team that studied the benefits in 1965. Dr. Thomas L Petty was head of the team at University of Colorado in Denver. Following the small original study we designed a larger program for out patients. The benefits were wonderful for patients with COPD. Since then others have shown the benefits for other lung diseases. It is very frustrating to see that reimbursement for pulmonary rehab programs and oxygen are constantly cut by

medicare and some other insurance companies. We and others have shown decreased use of in hospital admissions following treatment with pulmonary rehab and in some cases continuous oxygen therapy as well as over all improvement in health. It is amazing that the benefits are questioned 51 years later. What other therapy is questioned as is pulmonary rehab and oxygen therapy?

## Colorado: Joy G.

The day I made my reservations to fly to Columbia MO on November 14<sup>th</sup> 2016, I knew I needed to set up the service for my liquid oxygen in the hotel. I have liquid oxygen with a Helios marathon portable oxygen system for my secondary when I'm out of my home or traveling. I called Preferred Home Care my provider on November 14<sup>th</sup> and spoke with Alex he told me that my insurance did not cover oxygen for out of state travel. He gave me the name and number of a provider to call to arrange for my oxygen and I would be responsible for the cost also. I explained that my retiree coverage from Anthem Blue Cross Blue Shield was my Medicare and Medicare pays for oxygen when you travel. I called Aero Care Home Medical 1-573-761-5941 (25 miles from Columbia MO) and spoke with Brandy. Brandy listened to me ask me about my coverage and she explained to me that my provider was obligated to arrange and cover my needs for oxygen, they must follow Medicare Law.

I started researching my problem by reviewing Medicare regulations and my Anthem plan is not an HMO it is a PPO and covers out of network providers. I emailed a friend of mine who worked at CMS before she retired when I was working for the SHIP at the Division of Insurance to find out who is handling oxygen complaints. After I heard back from her, on November 29<sup>th</sup> I called my provider again and spoke with a gentleman he told me loud and clear that travel oxygen was not covered on my plan. I ask to speak to his supervisor, he told me that Edward was not in but he would leave him a message to call me the next day. I then called my insurance plan member service number and to verify that it was covered, I got a positive response. When he had not called by noon I called them and ask to speak to Edward. Edward told me that they had a company policy that did not cover oxygen when traveling for benies with an HMO. I explained that my plan was not an HMO but a PPO. He said that did not matter, I explained he could call Anthem provider services and gave him the number. He called me back later in the afternoon and told me that they agreed with him that I was not covered.

On November 30<sup>th</sup> I called CMS 303-844-2111 to ask who is handling oxygen now. She transferred me to Cecily; I left a message on her voice mail to call me with a message regarding my problem. When I had not heard from her I call another friend at CMS on the December 6<sup>th</sup> left a message. Dennis called me on the 7<sup>th</sup> and he explained they were having problems with their phone system since they moved back into the federal building. Cecily works from home and messages should go directly to her home phone but there have been some problems. He told me he would research and look into it since my travel was next week. Dennis called me back and told me that it had been referred to the plan to handle as an expedite case and they would be reaching out to me. CMS does not have authority over Retiree plans and they need to be handled by the plan. This afternoon about 1:50 pm I received a call from a Jennifer at Anthem she wanted to know what my problem was, my provider and what I had done so far. They should cover my travel oxygen

since I Have a PPO. I gave her Preferred's phone number and Edwards's name and what he had told me. She is going to contact them and get back to me probably tomorrow but it may be Friday. Her number is 317-XXX-XXXX (redacted for submission) if I need to call her. Also if she can't get them to agree she will work something out.

## Colorado: Roxlyn C.

I am COPD Patient who has pushed against my breathing limitations for many almost 17 years. My story began during the 2002 holidays, a pounding fast pulse rate and extreme blood pressure spike (while baking cookies) resulted in blood pressure meds and a stress test. It was during this testing the technician said my hands turned blue up to my elbows, she said it indicated a pulmonary problem. Many tests later, a diagnosis of COPD moderate obstruction, primarily bullous emphysema, diffusion problem, and, a ventilation / perfusion mismatch, plus in later years added on to that was bronchiectasis and late onset asthma: > (These "issues" caused ANY amount of moving to be a challenge at the 5500 ft. altitude where I live near Denver. I needed supplementary oxygen immediately! It arrived on Valentine's Day 2003, an E tank and a concentrator. Oh yuk! At the time I didn't know 'oxygen was better than chocolate!' Within a day of using extra O2, a miracle it seemed, **O2 for me equaled = energy!** Thrilling! No longer sleepy all day, or feeling exhausted by small exertions. Learning how to manage my disease, and what medications plus life style changes helped. Using an inhaler worked wonders, in addition to a supplementary oxygen flow of 3-15 L of oxygen. These all combined allowed me to slowly rebuild fitness from my severely deconditioned state. My muscles were very weak & endurance almost zero. I also had mild sleep apnea...Attending Pulmonary Rehabilitation shaped my discipline & dedication to exercise. Two years of slow, but steady small increments in moving to get back to my normal fitness level. My poor 44% DLCO (diffusion) causes my oxygen saturation to drop like a rock. I learned about the helpful - best tool - a pulse oximeter that can tell me if I'm maintaining a safe blood oxygen saturation level, any lower than 94% ones vital organs start to degrade for a bit, and below 88% may start permanent damage to vital organs. My personal Oxygen comfort level is 96% – 98%. I find this is **my** "Normal" saturation level. High flow oxygen we have at home is not dangerous. It might be in an incubator, underwater, or in surgical settings, but not our home use equipment - can't do that, it is too diluted with air around us. The ultimate best help to me physically was having a TTO = Transtracheal oxygen <u>delivery system</u>. That enabled me to do so much more – Before diagnosis I was not an athlete, it was after I started to use O2 I fell in love with events starting with a 6/10th mile - American Lung Association fund raiser.

I felt ALIVE! Muscles gained and endurance improved over YEARS, made <u>walking</u> a Half Marathon possible for me – at first pulling my oxygen tank on an old golf cart, then pushing a Baby Jogger Stroller that can hold 5 liquid oxygen portables. Not many my age (78 in 2016) will be hooked on athletic events. My choice is extreme, obviously NOT a fun goal for everyone, but what to do is something enjoyable **for you**. Others should choose to work towards a fun for them goal, perhaps to go sailing, dancing, a long shopping day or evening at a concert -. With time, perseverance, patience – even if it seems to be a glacial pace, improvement will follow. If you start at 8 steps, adding one step per week- 52 are then possible in a year- it might even get you out to the mail box, a super

goal if the start is with 8 steps. In the last 14 years I have done 10 half marathons, 11 Lung association stair climbs up 56 stories, circa a dozen – 5Ks and climbing the last 6.1 miles to the top of Mt Evans... 14,260 ft. elevation. Currently training to do those 56 stories a 12<sup>th</sup> time on Feb. 21, 2017. VERY SLOWLY keeping my O2 sats at or above 94%. Set your own personal goal and move a little bit more every day any which way you can... Compete with yourself. Do better, feel better. Finally it adds up to better breathing and living. The more you do, the more you can do. It will help delay the progression of COPD too. Have your medical team guide you. Mark Mangus (respiratory care specialist) told me, Keep moving, "any age, any stage" you'll benefit from exercise and gradually improve fitness – Dr. Tom Petty told me to "Titrate as I Migrate". It all WORKS! "Lyn" (Roxlyn G. Cole)

## Colorado: Felipe H.

I am an RT in Lafayette Colorado. When I see new patient inevitably I hear the same thing from about 97% "why am I just now learning about Pulmonary Rehab? Why wasn't I sent here a long time ago? I believe that with rehab, optimal medications, diet and good sleep people can control their disease they can have a decent quality of life. I have seen folks who have been able to halt the progression of this nasty disease. But so often I am seeing folks with poorly controlled asthma or with occupational exposures that have progressed to stage 4 COPD! This is preventable!!! Pulmonary Rehab is a life saver the sooner the better! People are suffering needlessly the cost of chronic lung disease could be greatly impacted if people had access to Pulmonary Rehab.

## Connecticut: Susan M.

My name is Sue and I am the Facilitator for Better Breather Club and lead therapist for Pulm Rehab in Torrington ct. Pulmonary Rehab has clearly helped many people who suffer from lung disease. By attending twice a week, while being monitored with exercise, attending education classes and socializing with others who have the same or similar diagnosis has been proven to help emotionally, and physically. This program is VITAL to all who suffer from lung disease. This has helped decrease ER visits and hospitalizations. I've been doing this for over 20 years and I truly feel, as therapists, We make a big difference.

#### Connecticut: David J.

Hello,

Here are 2 Pulmonary Rehab videos from our collection.

1: https://www.youtube.com/watch?v=gmHXy767-84

2: https://www.youtube.com/watch?v=nxBbQM3LCF8

Please let me know if these can be helpful to you.

#### Connecticut: Ruth.

I have asthma and frequent bronchitis. Pulmonary Rehabilitation has helped me tremendously!!! My breathing has improved due to the exercises there. I am able to walk further without getting out of breath. Therefore, the program is really helping me physically. The program is helping me emotionally, as well, because I feel better about

myself because I am doing something positive to improve my condition. Also, the staff are excellent, supportive and caring. I look forward to going to pulmonary rehab twice a week, and I wish it was at least three times a week.

#### Connecticut: Jean A.

I am in a Pulmonary Rehab group, and am loving it! At age 75, I am liking the benefits of getting into a Pulmonary Rehab Program. As well as learning to breath correctly, my joints and muscles feel much better too. I was first introduced to Pulmonary Rehab in 2002, as my husband was recommended to go. I have adult onset Asthma, and got permission to join him in the Education and Exercise Program too.

We continued thru the required weeks, and both felt better. Fourteen years later, my Primary Care Giver recommended I attend Pulmonary Rehab, to treat my shortness of breath after breaking a rib.

I was a caregiver for my husband with COPD. He was currently being treated in a Nursing Home for COPD complications. I now had the freedom to go to Pulmonary Rehab, to care for myself. He died from COPD complications and Alzheimer's Disease, I continue to go to Pulmonary Rehab, and enjoy the exercise, the staff, and the friends I have made there, to keep on going. My sister calls Exercise, 'Phy Ed for the rest of our lives'. I am learning to think that way to, and happy to find an exercise program that I enjoy, and learn many good ways to improve my breathing!

## Connecticut: Cherrie C.

I attend pulmonary rehab at CHH. I have COPD and this program has helped me breathe easier and keeps me motivated to go knowing they will monitor my oxygen levels and blood pressure!! I would be lost both physically and mental without this program!!!

## Connecticut: John S.

Please do not be penny wise and pound foolish. COPD was the diagnosis – my Pulmonologist recommended the Pulmonary rehab program at Hospital For Special Care in New Britain, CT.

I started in April 2016, weighed 247 pounds, and could not walk my dog to the mailbox! Six weeks of intensive education, exercise and helpful suggestions about coping with COPD was the answer in my case. Here we are in early December, I now weigh 198 pounds and the dog is barking for me to slow down! This is a lot better than spending another week in the hospital as I did last January – the bill was quite extensive.

#### Connecticut: David K.

I went through the Hospital for Special Care's pulmonary rehabilitation program in the summer-fall of 2015. The improvement in my COPD condition that I attribute to the program has been almost miraculous. My endurance and stamina are tremendously improved, and my episodes of shortness of breath and fits of coughing have declined markedly. Since completing their program, I have not required hospitalization or emergency room visits due to lung issues. The competence and dedication of their respiratory therapists is exemplary. After a dark period, I am now confident that I can live

with my disease and maintain a satisfactory level of activity. This is a fine program deserving of public support.

#### Florida: Russell.

I was diagnosed three months ago with stage 3 severe COPD, emphysema, and three weeks ago I started pulmonary rehab. Couldn't really tell much difference until I began weight training.

That made a big difference in my breathing and attitude. Not as depressed anymore and actually look forward to going. Made some friends and I really like my therapists, except for my psych therapist...I think I'm in love with her! ♥ Anyway, I'm glad I took everyone's advice on here and other places and joined a pulmonary rehab. I'm now doing some exercise at home also. I reccomend PR to everyone.

## Georgia: John H.

Pulmonary rehabilitation plays a very important part in the lives of those suffering from various pulmonary problems. In my case, suffering from COPD and related concerns, I have partaken of a very extensive and complete rehabilitation program over the past two years and attribute my being alive today to this exceptional program. I am afforded the use of various types of equipment and provided an oxygen supply, not available in public commercial facilities, that permits me to safely condition myself. The awareness of the benefits of conditioning is noted when this patient must miss exercise sessions. In addition to the physical benefits from rehabilitation are the emotional or mental factors that play an important role in the patient's well-being. The being a member of a group that endures the same pulmonary problems enhances the patient's abilities to face the daily concerns of coping with their problems. Other benefits include comparing solutions to problems, comparison of treatments, equipment, etc. rehabilitation centers should be manned by personnel equipped to handle the problems of the patients seeking assistance. The center I utilized is well staffed with a trainer possessing a doctorate degree and has lung and heart doctors readily available in the rehab facilities should a patient require medical attention.

## Idaho: Sammy.

I went to Pulmonary Rehab twice a week for about 6 weeks, so about 12 sessions. I have to drive 50 miles to and from to get there so with driving time and the exercise and group education it was about 4 hrs each time. I was quoted \$50.00 per visit would be my copay but I have yet to receive a bill. I stopped going this past week due to snow and icy roads and having to drive over a pass in northern Idaho. I certainly learned some things as far as checking my oxygen sats during exercise, adjusting my oxygen liters if necessary during exercise, pursed lip breathing. We did very little muscle strengthening. It was helpful but I felt that there was very little individualised attention. We usually had about 9 people in my class and 2 instructors (Respiratory Therapist and either an RN or an Exercise Physiologist). I would have like to have had a Physical Therapist. I had so many questions that no one seemed to have the time to answer. Some of the speakers in the 30 minute education class were very good and some not and again not much time to ask questions. I

will not continue to pay this amount of money and not be able to get some individualised attention and oversight and "customised plan" - I like the idea of the Pulmonary Exercise Program that Clip mentioned. So overall helpful but the 26 weeks or something to "graduate" seems very excessive to me - guess that is how many sessions that Medicare will pay?

#### Illinois: Harold W.

As a C.O.P.D. patient, pulmonary rehabilitation has given me a whole new life. I have suffered with C.O.P.D. for forty years. My lungs have collapsed 5 times and I have had two lung surgeries. I was at the point where everyday chores were becoming difficult. My doctor wanted to put me on oxygen. That was something I didn't want in my early 60's. As an alternative, he suggested pulmonary rehabilitation. I have now been attending rehab twice a week for 7 years. I am able to do the things I want and have participated in the Fight For Air Climb in Springfield, IL for 3 years. I am currently preparing for my fourth climb. I credit pulmonary rehab for keeping me off oxygen and allowing me to do this.

## Illinois: Larry Riley.

My name is Larry from Springfield Illinois; I was hospitalized in April 2016 with pneumonia and was sent home with oxygen. I thought I could manage the oxygen use with my primary general doctor and soon it was agreed my oxygen use wasn't needed. After a few months I realized my breathing and energy level wasn't getting any better and was referred to a pulmonary doctor. I had several tests done and was diagnosed with COPD and emphysema. I was prescribed oxygen with activity and at sleep. The doctor also prescribed pulmonary rehab. After my first meeting with rehab I realized I should had done this after first getting out of the hospital. It is now December 2016 and after 2-1/2 months of rehab I have learned some valuable lessons. Not only has rehab taught me breathing techniques they have shown how much exercise can keep my strength up. Please do not take this valuable medical need away from medicare.

## Illinois: Suzy.

Hello-- My name is Suzy, a 69 year old severe asthmatic since childhood which has become COPD over the years. I have been going to the Pulmonary Rehab program of Memorial Medical Center in Springfield, Illinois for seven years. I can't imagine where I would be without that program. I experienced great improvement in my breathing and emotional attitude from the very beginning. Continuing the program all this time has kept me from sliding back and reassures me when I have an exacerbation of my condition of my condition that I know my rehab class gets me back to where I was much quicker. The physical and emotional support of the nurses, exercise specialists, and fellow patients is invaluable as I live with my lung disease.

## Illinois: Mike O.

My name is Mike. I live in Springfield, Illinois. In October, 2014 I was stricken with "community acquired MRSA pneumonia". After six days in intensive care and 12 days in the hospital I was left with lung damage requiring lots of meds and oxygen therapy. I have been blessed to have a pulmonary rehabilitation facility near my home. It has been critical

to keeping me active and hopeful. I appreciate that the regular schedule helps with otherwise inadequate self discipline. In fact, I now look forward to the sessions and feel guilty if I have to miss for any reason. Without the oxygen offered there, I would not be able to utilize the wide variety of equipment available at the facility. Having the oversight of qualified nurses and therapists is an important advantage over what might otherwise be unsupervised and inappropriate exercise at a gym. The rehab has been critical to my ability to maintain a reasonably active life. No trips to the Emergency Room in over 2 years!

#### Indiana: Jennifer N.

As a respiratory therapist and nurse who works in pulmonary rehab, I see every day the benefit an exercise program has on those with chronic lung disease. Almost without exception, patients report improved ability to function in their daily lives and increased well-being. The education component helps them understand how to manage their disease better. Patients tell me often, however, that without the structure of a program they find it difficult to start exercising. Many are afraid to exercise on their own at home, or are not sure how to start. Others don't believe they even can exercise, and are amazed at what they accomplish in pulmonary rehab. Unfortunately, sports facilities, personal trainers and gym memberships are often out of reach financially for most of my patients. Many studies exist that show that pulmonary rehab is a proven therapy, and is also cost effective when compared to medications, frequent doctor visits and hospitalizations. Unfortunately, Medicare compensation for pulmonary rehab has continued to decline, putting programs in jeopardy. Again this year compensation is set to go down. I would strongly encourage those in power to re-evaluate this bewildering reduction in compensation. What we do has real value in terms of patient health and quality of life that is no different than the same service offered to cardiac patients (cardiac rehab). Why do those of us fighting hard to improve the lives of those with lung disease have to ask to be paid enough to cover our expenses?

## Iowa: Jean.

I've never done PR, but exercise has certainly made a huge difference in my life. I started exercising in 2003 and developed a habit that I maintain. I've switched to doing a lot more strengthening exercises than aerobic just recently, and am convinced that we should make far more use of weights and strengthening techniques in PR than we currently do. By toning the muscles, we allow ourselves to do a lot more with a lot less effort, and actually make it easier to do the aerobic stuff.

#### Massachusetts: Marcia.

My PR in Boston. Saved me, I was out of work for 10 months, in and out of hospitals and thought I was dying. After PR and education about COPD helped me go back to work full time, feel awesome, a lot of fatigue. I do walk and should be doing more it helps me so much. My Insurance covered PR and the Hospital had a van to pick us up and drop us off. Thank goodness, I would have never gotten there. I want to try and go again, it's been over a year, i just need to work something out with my job.

## Michigan: Denzie.

After learning that I might qualify for pulmonary rehab at a lung cancer conference in Columbus, Ohio I asked my primary care dr for a referral to receive it. She sent me back to the pulmonologist who I had not seen since the week that I was diagnosed. (This was just about 2 years after I was diagnosed. I present pretty well. Unless I've been walking or working hard you would not look at me and think I am a cancer patient. The pulmonologist told me she didn't think that I was qualified as I appeared too healthy to her. I persisted and kept emphasizing the damage my radiation did to my lungs in the course of my cancer treatment. We did the interview and I answered a myriad of questions about using stairs. walking, exercise, self care and inhaler usage among other thing and she relented. She ordered the full battery of tests and told me she was only doing it to establish a new baseline. The nurse who called to schedule was also skeptical and told me flat out that she did not believe I would qualify. The test came and I gave it my best. A few days later I got a call from the nurse who told me there was good news and bad news. The bad news was that I had copd and qualified for pulmonary rehab. The good news was that I did have copd as I believed and I qualified for pulmonary rehab. The doctor wrote the order but told the nurse to tell me not to bother coming back to see her when I was done. In rehab I was taught pursed lip breathing. Also exercises that helped strengthen the muscles that support breathing and increased stamina. My overall strength and stamina have improved. I wished that I'd had it before I did Livestrong as I think I would have gotten more out of it. Often when I'm talking to survivors who've recently completed treatment I recommend that they request a baseline PFT to qualify for pulmonary rehab.

## Michigan: Mike.

Anyone with severe COPD that wants any type of quality needs to do pulmonary Rehab. I've been doing it since 2000 when I was at University of Michigan for transplant consideration. They wouldn't do transplant because issues with my heart at that time my FEV1 WAS 24%. They said life expectancy was 2 yrs, but that's what there research tells them. I'm now at 18% and still mow grass, weed wipe, shovel snow, run my snow blower and best of all still manage to put 10 to 12 thousand miles on my motorcycle a year (not easy living in Michigan). Do i credit this to PR yes and no. It teaches you what you need to know to survive this horrible illness but YOU have to put the work in (mental and physical). I'm on O2 most of the time as i can still walk in a restaurant and eat and a go in few other places, but believe me not doing any dancing lol. 6 to 8 liters while exertion. Is life easy absolutely not but it's all I've got and it's worth fighting for even if the quality is not that great. Everyday is a gift that's why we call it the present.

#### Minneapolis: Kris M.

I am the coordinator for our outpatient pulmonary rehabilitation program in a medium size hospital within a metropolitan city. Through my 25 years in this setting, we have increased our patient population to our current levels of 200-225 patients/year. Pulmonary rehabilitation offers so much to participants and is viewed highly by our medical community. Patients come into pulmonary rehabilitation not fully understanding their lung diagnosis, pulmonary medications, and their potential for improvement to manage and care for themselves. Our staff spends valuable time with

each patient to reach their goals and help them decrease their anxiety of living with their shortness of breath on a daily basis. Patient's attending pulmonary rehabilitation get further help with their pulmonary medication adherence including the proper technique of use. This increased understanding and compliance with their pulmonary medications allows for their ability to remain out of the hospital. Assessing oxygen needs and helping those patients who need supplemental home oxygen is a big part of our pulmonary rehab program. Weekly, we are finding patients set up on the wrong oxygen system that is not meeting their needs with activity. These patients then become less mobile because of their low oxygen level and breathlessness. The inactivity continues to perpetuate the cycle of dyspnea and a sedentary life. It is important to help patients in this situation early due to the constraints of being able to change oxygen providers or equipment once a person has been set up. We play a valuable role in helping patients get on the right oxygen system and resume their ability to return to work and/or be able to leave their home. We work closely with all our home oxygen providers in meeting the needs for the patients. There are many additional areas of focus in pulmonary rehabilitation from nutrition, exacerbation prevention, stress, relaxation, strengthening and sleep that benefit all the patients referred to pulmonary rehabilitation. Each patient learns valuable skills to care for themselves and prevent an exacerbation from reaching the point of a hospitalization. All of the components of an AACVPR certified program allow for patients to benefit from pulmonary rehabilitation. These components are brought together when outcomes are measured and tracked with each patient. Patients in pulmonary rehabilitation gain confidence in their ability to maintain their activities of daily living. They are able to do their grocery shopping, laundry, and move around their community. Patients who once thought they could not attend a grandchild's music concert or sporting event are surprised to find they can enjoy such outings with their family. Reimbursement for pulmonary rehabilitation is necessary for all programs to accomplish our certification requirements in meeting the many needs of our patient population. Please re-consider the 2017 final reimbursement decision.

## Minneapolis: Peggy T.

The benefits of pulmonary rehab have impacted my life. Going to the sessions taught me so much about my condition (exertional dyspspnia) and steps to take to cope with it. Continuing every-two-months meetings of the Better Breathers Club gives me a chance to see some of the same people, who share their problems and experiences. Our group meetings also spur us to continue with good habits. Pulmonary rehab sessions showed me what condition I was in, and how to work to keep in shape. How to handle stress is another helpful benefit. I think pulmonary rehab is an important treatment for pulmonary lung problems. I am grateful to have received this help.

#### Minnesota: Betty P.

I am Betty diagnosed with COPD eleven years ago. I attended the North Winders rehabilitation program run out of North Memorial Hospital in Robinsdale, MN. It was a very intense program with and two hour a week educational component for the entire group. Then two times a week each member of the group was scheduled one-on-one with a respiratory therapist for physical therapy. Each person was monitored continuously by

this therapist to evaluate our progress and saturation levels. We increased our strength, time and ability to exercise daily and know what level of oxygen to be on at the time. Adjusting the oxygen level to our need was one of the more important components in my estimation. After graduation they continue with a monthly program that encourages exercise, information on medications, adaptations in our lives that will let us live longer, and any other pertinent information related to our status as a ÇOPD patient. The initial doctor that did my complete workup and gave me the diagnosis had given me 3-5 years to live. I was in the severe range when diagnosed. I have made it eleven which means I was able to be around this many more years for a handicapped son. These programs are so very cost effective. I have NOT been in the hospital at all inf the eleven years compared to some friends who have not taken part in such a program and are in the hospital 3-4 times per year. I hope this helps those in power to realize rehab programs are very cost effective.

#### Minnesota: Rachel C.

This is a letter on behalf of myself and our Pulmonary Rehab Program and Pulmonary Rehab Support Group at Allina - Unity Hospital. My name is Rachel Cox, Unity Hospital Pulmonary Rehab Coordinator, and I felt it is my duty to speak up on behalf of our healthcare providers, patients, support givers, and families in our community. Pulmonary Rehab is very effective in helping respiratory patients and reducing hospital readmissions. We have proven this here at Unity with our Pulmonary Rehab program being so effective that our hospital readmission rates are extremely low. After attending Pulmonary Rehab for 6 weeks, patients leave with a new outlook on life. Pulmonary Rehab is a comprehensive program that includes: lung anatomy education, disease education, breathing techniques, smoking cessation plans, medication education, exercise (including cardiovascular and resistance training), nutrition importance, relaxation techniques, stressors and anxiety relievers, communicating with your healthcare provider, goal setting, and an action plan. Our 6 week program has been designed to help patients make changes to have a better quality of life. In 2016, to date, we have discharged 59 patients with great results. Upon entry into the program patients complete a Pulmonary Stress test. They complete another Pulmonary Stress Test before discharge. In 2016, our Pulmonary Rehab patients were able to increase their walking distance by an average of 67.71%. Additionally, when looking at their exercise statistics our Pulmonary Rehab patients had very positive results. \*they could walk an average of 78.77% longer \*they could walk an average of 109.95% further. They were also able to increase their Metabolic Energy Equivalents (METS) by an average of 27.62%. When looking at their Upper Extremity exercises (Arm Ergometer) they were able to increase their duration by an average of 109.29% and increase their METS by an average of 26.33%. These are very important as these are the muscles these patients use to breathe. When looking at their Lower Extremity exercises (Nu Step) they were able to increase their duration by an average of 101.93%, total steps by an average of 150.07%, and increase their METS by an average of 22.72%. This is importance to keep these patients active and moving. Additionally, measures such as the Duke Health Profile (DUKE) and the Patient Health Questionnaire -9 (PHQ-9) are utilized to evaluate mental health and depression. Patients whom graduate from Pulmonary Rehab programs almost always have less depression, less

anxiety and a better quality of living. When evaluating Pulmonary Rehab programs, you need to look at the big picture. Patients are filling their medications and understanding how and why they work. Medication compliance is imperative to reduce hospital admission rates. We follow the National Guidelines set forth by GOLD (Global Initiative for Chronic Lung Disease) and help promote adherence of these guidelines set forth by evidence-based medicine. The rate of one hospitalization for a COPD patient is over \$20,000. The cost for one patient to attend a Pulmonary Rehab program is far less with results that are proven. Pulmonary Rehab programs are very busy with waiting lists to enroll. We currently have over 60 patients waiting to enter Pulmonary Rehab at Unity Hospital alone. Pulmonary Rehab is an imperative and necessary part of care for this patient population and especially important when considering our healthcare expenses. I strongly to encourage you to reconsider the reimbursement rates and do the right thing for our patients. Pulmonary Rehab, in fact, needs additional reimbursement, not less. This in turn will reduce the overall amount of healthcare expenses (hospitalizations, Emergency Room visits) for this patient population.

#### Minnesota: Bill T.

I have been through this program and it is an absolute necessity to continue this program for those with respiratory issues. Centra cares program was excellent with In Depth discussions, guest speakers and physical fitness exercising. It was and still is a tremendous asset to me on a daily basis. Please consider continuing this program as is for the benefit of those in need. Jessica Oman the programs head person does a great job.

## Minnesota: Jennifer U.

I am writing today to ask that Pulmonary Rehab programs be given the support they deserve with an increase in the reimbursement rates. I am a respiratory therapist, now in management. I have a rather large file of patient feedback from the Pulmonary Rehab program that I manage. It is full of documentation from participants about how much they benefitted from the program. How much their quality of life has increased. How they are avoiding hospital stays. How they've observed reduction in other ailments as well as the pulmonary diagnosis that lead them to the program, such as depression, anxiety, and pain. The majority of our participants are on a fixed income. To deny them this service by decreasing reimbursement rates would be an absolute shame. It will also probably lead to an increase in hospital admissions – which is going to cost way more than a pulmonary rehab program. Pulmonary rehab programs are an effective, efficient way to contribute immensely to patient health, wellness, and quality of life. Please support this with reimbursement

## Minnesota: Carol L.

I don't know what I would have done without the pulmonary rehab program at Fairview Hospital here in Minneapolis. I had been diagnosed with C.O.P.D. about a year earlier, and had already made two trips to the emergency room with exacerbations, plus was having trouble working. The program taught me skills of daily living, specialized exercises, better use of my medications, and more. I've never had an exacerbation or problem working since, and it's been four or five years now since I "graduated." Based on my experience, I

suspect Medicare saves money on pulmonary rehab by preventing expensive visits to the ER without it, and possibly even nursing home or home care costs for those no longer able to work or take care of themselves because of their breathing problems.

#### Minnesota: Jamie T.

I have Alpha 1 Antitrepsin Deficiency and have depended on Pul. Rehab. to try and slow the destruction of my lungs, by participating in Pul. Rehab. PLEASE do not reduce reimb., or think about eliminating this valuable and life-saving resource. It keeps me from being hospitalized where the costs would be astronomical compared to being able to do Pul. Rehab. I am at 22% lung capacity and know that I would be much worse without being able to participate in Pul. Rehab. Alpha 1 patients, COPD patients all benefits and keep costs down for Medicare.

#### Minnesota: Patricia P.

My name is Patricia, age 78. I have COPD, using 2 liters oxygen, 24/7 and have for 16 years. In pulmonary rehab, I learned how to correctly utilize the prescribed inhalers (3), what exercise to do to keep my condition from deteriorating, how to recognize the onset of an exacerbation and in doing so, avoid a hospital stay. I believe every pulmonary patient, certainly at my level of disability should attend a pulmonary rehab and perhaps more than once. Therefore, I think not making the rehab available to patients such as myself at a reasonable cost whether it is covered entirely by Medicare/Medicaid or with a patient's co-pay would cost far more in the long run due to frequent hospital stays and faster deterioration of the patient. COPD and asthma patients both benefit, have a better quality of life and avoid hospital stays more often. In my personal experience, neither doctors nor pharmacists provided even minimal instruction in using inhalers or breathing techniques. These are vital services were provided by rehab specialists. For these reasons, I am asking, please do not cut any funding.

## Minnesota: Mary P.

I have not made one trip to the emergency room since taking the St. Cloud Hospital's excellent course in pulmonary rehab in 2012. Learning pursed-lip breathing was key to overcoming what I had always considered symptoms of heart trouble. And the heart is involved when we have breathing problems. In the long run, and the short, the course was an economy. Please do not short-change it.

#### Minnesota: Joe M.

My name is Joe and I have COPD. I was involved in the Pulmonary Rehab Program at the St. Cloud Hospital after I had collapsed a lung in 2013. My experience with Jessica and her colleagues was a life changing experience for me. My mother also had respiratory issues several years prior to that and had gone through the program as well. I saw the difference it had made for her on a daily basis. Jessica, had demonstrated to myself and the others in the group how we could all lead a better life by the processes that she had taught us. As the program went on, I could see and feel the difference the program was making in my everyday life. She taught me to think about my everyday issues and the skills to counter act the problems. She taught me to do the simple things differently so I would be able to

do more without being so worn out at the end of the day. They set up exercise program for me that has built up my endurance and has improved my lung capacity. From the start of the program to the end of it, I experienced a big change in what I was able to do on a daily basis. Even now at 3 years after I finished the program, I am breathing easier and living better than I was prior to going through the program. I was very fortunate to have Jessica and the program available to me in my time of need. I would highly recommend the Pulmonary Rehab Program to all that have respiratory issues, it made all the difference in the world for me. Thank you for taking the time to hear about my experience.

## Minnesota: Cheryl S.

I facilitate two support groups for adults with chronic lung disease. It Never Fails that when a new member joins our group, the experienced members share their wisdom with them and one of the first things they ask is, "Have you been to pulmonary rehab yet?". Adults with chronic lung disease know the value of these programs as they reap the benefits of improved exercise capacity, improved quality of life and decreased anxiety and depression associated with COPD. Many clinical trials have proven the benefit of pulmonary rehab. The Cochrane Review published in 2015 was a meta-analysis of 65 studies and nearly 4000 participants. It showed a statistically significant improvement in quality of life for dyspnea, fatigue, emotional function and enhanced sense of control. Both functional exercise and maximal exercise showed statistically significant improvement. Reimbursement levels for pulmonary rehab are low and putting programs in danger of continuing. As hospitals are facing penalties for COPD 30 day readmissions, they desperately need pulmonary rehab programs as a bridge from the hospital to the community so they can help keep patients out of the hospital. The cost of participating in an outpatient rehab program is significantly less than the cost of a COPD hospitalization (\$20,000). More importantly, patients learn skills to learn how to live with their lung disease and they connect with others dealing with the same struggles. It is crucial that you increase funding for pulmonary rehab programs!

## Minnesota: Linda.

Three and a half years ago I was in the hospital unable to breath.. I was put on Oxygen and thought my life was over.. COPD they told me. After a few weeks I could get by without oxygen at home but I still felt my life was over.. I was told to try rehab.. I SIGNED UP AND GOT MY LIFE BACK.. Exercise they told me, they are nuts I thought.. I loved it along with the education on medication the difference in kinds of copd, how to improve breathing and more. If funding is reduced for Pulminory Rehabilitation many lives will be affected.. I would have been running to the Dr constantly because I would have been uneducated on this disease.. My medical bills would have climbed.. Please help others learn their lives are not over you can still do many things and there are ways to make breathing easier.

## Minnesota: Julia S.

I am the Respiratory Care Supervisor and head of our Pulmonary Rehabilitation program in our 25 bed rural critical access hospital. In January I had a gentleman come into the program who had no idea what his lung disease was or how to breath properly and had

been in the hospital for pneumonia. He started the program as soon as he was able and he was able to go from not being able to walk 50 feet to being able to walk over 800 feet by the end of the program. He did have a hospitalization requiring him to go to a larger hospital for blood clots shortly after he started in the program but we were able to get him back in within a month once he was cleared by his medical physician. While he was in the larger hospital he told me how he bragged us up as to how we had helped him breathe easier and understand how to do his daily activities better and also were able to get him weaned down on his oxygen. He understands when he needs to go in and see his doctor before he has to be hospitalized and is doing excellent at home and has become even more active than prior to his beginning the program. None of my current patients are good with a computer so I am writing their stories for them. In the last 6 months I have had 2 patients who have completed the program and 1 currently in the program. Prior to starting pulmonary rehab none of these patients really understood much about their lung disease and were pretty much staying at home and not enjoying any social activities. We were able to get all patients more active and exercising regularly at home. 2 of the patients were on portable systems that made it difficult for them to go out for longer periods of time without taking several tanks with them. We were able to get them on a different system with a battery backup and they are now able to go to church and shopping and other social events with much less stress about running out of oxygen. Initial depression scales on both patients were in the moderate to concern levels and now both are feeling more productive and less depressed because of their lung conditions. Initially all 3 patients were reluctant as they really did not understand what rehab would do for them but as we worked with them they enjoyed the time educating, socializing and exercising. My current patient stated yesterday that he is able to do more and feels much better and has started exercising regularly at home.

I have seen patients who felt they could only go from the chair to the bathroom become stronger and more secure and able to now go out and enjoy their lives and not feel they are a burden or would be better off dead. It is so rewarding to see patients smile and enjoy coming to rehab and also has helped them socialize with other patients who are in the same situation as they are. In our program we schedule patients every half hour so one is finishing as one is starting and it is fun to see how they bond and develop friendships they would not otherwise have made.

I started my program about 10 years ago and remember my Medical Staff being unsure how the program would help their patients. My first patient was a gentleman who was only 63 and at that time was told he only had about 5 years to live as he had severe COPD. He was able to live a full and productive life for another 12 years before he lost the battle and continued to do as much exercising as he could until the end. His wife also benefited as she also developed severe COPD and they would coach each other at home. Pulmonary rehab is a very vital program for all patients whether they have COPD, Asthma or Pulmonary Fibrosis. We are able to spend time with our patients to really educate them, monitor them and instill a sense of confidence they have lost due to their lung disease. We can teach them when they need to see their doctor before they become so ill they need to come in by the ambulance to the ED due to pneumonia or COPD exacerbation. Patients are able to see how the program helps them within a few sessions and in the end gives them a better quality and even quantity of life. When you have

people who are low on oxygen they need more time and patience to help them understand why they need to keep using their medications and not to stop just because they feel better. We can also monitor them and detect problems before they require hospitalization. I have seen my Medical Staff go from skeptical that rehab can benefit these patients to suggesting it and asking me to contact patients to get them involved in the program. We need to continue to do pulmonary rehab programs for our patients as in the long run it is very cost saving and also insures a better quality of life for people with breathing issues.

#### Minnesota: Trudie M.

I have been told that reimbursement for PR programs is in jeopardy. Please reconsider. This program helped me so much. It not only teaches you about lung disease but also about how to live with your disease and stay healthy. I learned about nutrition, exercise, breathing exercises, medications available for my condition, not to mention learning tips and ideas from the patients who are in the program with you. It is always nice to know you are not alone in your struggles too. This program is something that all COPD patients should be provided if they choose and if their dr. thinks it would help them. The program offered to me at the St. Cloud Hospital in St. Cloud Minnesota was extremely well run and the facilitators were knowledgeable and did a fantastic job. This is a great program and i believe the things i learned in the classes has helped me be healthier and stay healthier which in turn keeps me out of the doctors' offices and hospital, saving my insurance company money in the long run.

## Minnesota: David G.

In the last twenty years I have been in the rehab program twice. Each time It was as important as the medicine I was receiving. I have COPD, my lungs hardly work, when the tests came back, I was told I have only ten present lung function. I need all the skills that can be offered. I get to live a very good life with the skills I have learned. Because of their hard work and encouragement I ride a exercise bike at least five days a week five miles. I still do secretary work for our business, enjoy my family and friends. The end of this month my husband and I will enjoy our 50th wedding anniversary and looking forward to going on an Alaskan cruise next summer. That rehab program will put people lives back in focus. We have a disease that needs to be managed and the program will help.

#### Minnesota: Anne U.

High quality Pulmonary Rehab programs are essential for patients living with chronic lung disease.

Pulmonary Rehab helps build exercise tolerance and endurance, which is essential for their overall health and wellness. By the time we see most patients they have so drastically modified their lifestyles that they are completely sedentary and making poor nutritional choices daily. This has a profoundly negative impact on their overall health and drives up medical costs. Most of our patients also have diabetes and cardiovascular disease. Exercise, which they get in Pulmonary Rehab, is proven to help these conditions. For our patients with diabetes, we monitor their blood sugar levels when they arrive and with exercise. We have been able to intervene early and prevent these patients

from going to the Emergency Room. We also ensure that learning about nutrition is catered to their comorbidities.

People are educated on what their disease process is, how to cope, how to exercise, how to recognize and treat symptoms/exacerbations, understand the various types of tests they may encounter, how to properly manage their oxygen therapy, how to travel, how to eat well, the importance of tobacco cessation and how to quit, what to expect in the hospital and how to successfully return to home, as well as end of life issues.

## I have witnessed Pulmonary Rehab:

- Allow an individual in their 30's to return to full-time employment. This individual has such poorly managed asthma that they were unable to work. After Pulmonary Rehab where they learned about disease management, medication therapy, proper nutrition and an exercise program this person was able to lose a significant amount of weight and return to living an active lifestyle.
- Help an individual who was unable to walk from their living room to the front door without stopping to rest, build their exercise tolerance to a point where we couldn't get them to stop exercising to check their vitals.
- Reduce hospitalizations by teaching patients how to recognize changes in symptoms and call their physician's office for a visit before they access the Emergency Room.
- Reduce hospital length of stay. When patients in Pulmonary Rehab have been hospitalized, they have verbalized that they better understand what to expect and are more willing to adhere to treatment plans to get home sooner. We have had patients return to Pulmonary Rehab the day after their hospital discharge because it is so important to them and they know that it makes a difference in their life.
- Allow an individual to resume the world travels that they loved. They thought traveling was no longer an option for them because of their lung disease. This person just returned from Europe and "had the time of their life".
- Build friendships, support groups and accountability partners. People in the program together feel comfortable talking about end of life issues. They go out to eat together and remind one another to make proper nutritional choices.
- Help patients understand Advanced Directives. It is shocking how many people
  have no advanced directive or advanced directives that they don't understand. In
  every session there is someone who says "that's what that means?" or "that's what I
  signed?".
- Help people reduce or completely eliminate their use of supplemental oxygen.
- Utilize their medications properly to reduce waste or properly manage their specific condition.
- People travel over 100 miles per day, twice a week to attend Pulmonary Rehab because they experience the positive effects from the classes.
- Go from multiple readmissions per year to zero hospitalizations!

Pulmonary Rehab is essential to the well-being of individuals with chronic lung disease. Reductions in reimbursement will force programs to close across the country and

take this valuable resource away from individuals who want to live a healthier lifestyle, manage their disease state and reduce their dependence on the healthcare system.

#### Minnesota: Samantha K.

As a Respiratory Therapist, I have seen such drastic differences in patients both physically and mentally post pulmonary rehab. Most of the patients I deal with have such a knowledge deficit about their illness and medications in part due to the lack of time physicians and healthcare professionals are willing to spend discussing it with them. I have had individuals who have held a COPD diagnosis for 10+ years that finally learned how to use their inhalers correctly during class. The education about recognizing exacerbations and catching them early (decreasing the amount of ER visits and hospitalizations) have kept chronic lung disease patients in the clinic setting and out of our hospitals. The other side of everything is how much more confidence participants have in themselves and their abilities post rehab. Most come in depressed and have admitted to limiting activities due to shortness of breath or embarrassment of needing to wear oxygen. I have heard my patients tell me that they've gone back to golfing, meeting up with friends and exercising at home because now they know how to better control their symptoms. By decreasing reimbursement in Pulmonary Rehab, you are telling people that you don't care about people's wellness and quality of life. Preventive care helps keep our patients out of our hospitals and puts them back in our communities; making them stronger than before.

## Minnesota: Whitney Q.

As a pulmonary rehab therapist, I have seen the program's benefits in countless patients. We track patient outcomes in the AACVPR Pulmonary Rehab Registry. Here is a summary of the patients that completed pulmonary rehab at our facility since we started using the Registry in 2014:

6-Minute Walk Test distance improved 14%

6-Minute Walk Test METs improved 9%

Borg Shortness of Breath improved 25%

MMRC dyspnea rating improved 50%

Global quality of life based on St. George Respiratory Questionnaire improved 15% PHQ-9 depression score improved 14%

## Minnesota: Jenny K.

Lakeview Hospital is fortunate to have an outpatient pulmonary rehab program. Our program has grown exponentially over the last 3 years, with almost 100 graduates each year. During the last 2 years, Lakeview Hospital has had ZERO COPD exacerbation readmissions, 30 days after discharge. I firmly believe this is due to the extensive education and exercise provided to the patients of our pulmonary rehab program. Learning to manage their chronic lung disease with proper exercise, nutrition and medication management prevent repeat hospitalizations and allow our patients to retain their desired quality of life. While the proposed increase in pulmonary rehab reimbursement is being evaluated, think about the total cost of care delivered to our patients. What price is reasonable to keep patients out of the hospital? To keep patients active, living well in their communities? What about the social, supportive aspect of the

program? Where else can you provide direct patient care, education and support for a cost that is well below the alternative hospital stay? Our healthcare focus needs to switch to preventative medicine and programs. If we teach our patients to take care of themselves, they will! However, some programs will not survive the decrease in reimbursement that is being proposed.

#### Minnesota: Lori S.

Pulmonary Hypertension took my breath away. Pulmonary Rehab gave it back. When I was first diagnosed with Pulmonary Hypertension (PH) I could walk only a short distance before becoming out of breath. Doing routine activities like laundry, getting in and out of a car, even showering were a struggle.

Pulmonary Rehab changed all that. Today I follow a 4 times a week workout routine devised by my Respiratory Therapists from the Pulmonary Rehab program. I am active on several committees at my local hospital. My husband and I are able to get out to various activities, concerts etc. None of that would be possible without Pulmonary Rehab. It was there that I learned better breathing techniques, increased my stamina, began a regular exercise program, and improved my quality of life in general. When I first started the program, I could not speak at all while walking on the treadmill. Now I happily carry on conversations with my fellow exercise buddies as we walk! My doctors tell me that Pulmonary Rehab and my continued commitment to what I learned there is why I am doing well with what is a progressive disease. As newly diagnosed patients join our PH Support Group, we share with them the benefits of Pulmonary Rehab, and those that sign up say it was the best thing they did (aside from medication of course) to manage their disease. Current and future patients risk losing all these proven benefits if reimbursement rates are cut. That will translate into fewer programs, especially in rural areas. I urge CMS to reconsider cutting reimbursement for this vital service that produces proven, documented results, and to reinstate payments that reflect the results that Pulmonary Rehab consistently delivers..

## Minnesota: Jennifer H.

I work at Lake region Healthcare in Fergus Falls, Mn. I have worked here for 15.5 years. I have been a respiratory Therapist for 20 years. I am a BBC facilitator. We currently have a Pulmonary Rehab program. We have had one for 20 plus years. Our community is mainly older retired folks. Many COPD patients that live within the community. I have seen many patient's quality of life change for the better because of our Pulmonary Rehab program. We continue to see these people at out monthly BBC meetings. With the education provided at Pulmonary Rehab, patients carry that information with them to help them understand their lung disease. I am writing because I see daily in patients on how their quality of life is great because of Pulmonary Rehab. Thank you Jennifer Herzberg.

## Minnesota: Maren.

I was diagnosed with COPD in 2007, and generally ignored my doctor's advice to quit smoking and to start using daily long-term inhalers -- until the summer of 2008 --when I developed a good case of walking pneumonia, and also decided it was time to retire from

the work world. My doctor then convinced me to start using inhalers, and suggested that I try Pulmonary Rehab, and since I was starting a new retired life, I agreed. It was the best thing I did! By the time I had completed six weeks of exercise training and education, I had quit smoking (finally!!) and had increased my exercise capacity from 10 minutes to around 30, albeit slowly. (This was a health plan covered benefit, since I was still under 65 at the time.) I also participated in their support group, as well as the American Lung Association support group, with helped me survive the downs associated with trying to exercise every day. Since then, I have had refresher sessions (through Medicare) in Pulmonary Rehab following a spell in the hospital for pneumonia following cancer surgery, and more recently, after recovering from a pelvic fracture. These were shorter rehab sessions, but provided the support I needed to keep pushing myself to regain the stamina I had lost during health declines. They also helped me adjust to the oxygen that I eventually needed to use. I continue to exercise almost daily for 40 minutes on an elliptical machine in my basement, along with some arm weight work, and continue to enjoy involvement with my support groups. My doctor has told me that the way to stay healthy and out of the hospital is by regular exercise. I suspect I might not be here today without the Pulmonary Rehab program at Methodist Hospital. Please continue to support programs like this for the wellbeing of all of us lung patients!! We'd like to enjoy an active life for as long as possible!

## Minnesota: Sandy K.

- 1. Dorothy P says: Pulm Rehab taught me how to breathe with my bronchiectasis. Every day is better, not being so afraid.
- 2. Dorothy says: Yes, pulm rehab has improved my physical and emotional health by opening up thoughts on relaxing
- 3. Margie says: Pulmonary Rehab has definitely improved both my physical and emotional state with the new skills I have learned
- 4. William says: I'm just glad someone cares about my physical and emotional health
- 5. Vonnie says: Pulm Rehab has helped both my physical and emotional health
- 6. Donna says: I am much happier and relaxed, and have been able to accept my lung disease and deal with it.
- 7. Walt: Pulm Rehab makes me feel more confident
- 8. Rita says: Pulm rehab makes me happier.

#### Mississippi: Anonymous.

PT was not mentioned to me when I was diagnosed with Stage 3 COPD a little more than 3 months ago. After reading of the good PT seems to do on this site, I called and asked the 'phone nurse' to ask my doctor to send an order if it was appropriate for me. She called back 3 days later and said the doctor was taking care of it. Two weeks later the nurse

called and left a message on my answering machine that she had called the pulmonary rehab that is 20 miles from my house, and they would be contacting me. That was 3 weeks ago. I think I'll give them a call to see if anything is going on there for me. I have my second appointment toward the end of December, so I have a lot to unload about!!

#### North Carolina: Deana.

My name is Deana and I am registered respiratory therapist. I work in a small rural pulmonary rehab center in eastern North Carolina. I have been a respiratory therapist going on 19 years with 8 of those being in the pulmonary rehab setting. I see first hand the difference pulmonary rehab makes in peoples lives. I have seen patients start pulmonary rehab first attending in wheelchairs because they are to debilitated to walk into our gym. Upon completion they are no longer needing any ambulatory assistance. I have seen patient's supplemental oxygen discontinued. I have heard patients saying they can walk to their mailbox now and not be short of breath. The positive impact of pulmonary rehab centers are endless with physical, emotional and psychosocial benefits. Pulmonary Rehab is an important asset to our hospital and community."

#### North Carolina: Meredith.

"I took Pulmonary Rehab in 2012. It was very educational. We were taught the proper way to breathe. The importance of daily exercise. The importance of seeing a doctor immediately at the first signs of illness, that there are many types of lung problems yet each with many things are in common. The importance of being your own advocate. Also we learned how cold/warm weather effects your breathing. The list can go on and on. Our instructor, the respiratory therapist was very good at her job as well as the nurses, dietician and social worker. I also attend our Better Breather's Club and enjoy it. Our speakers have been good and I continue to learn about my lungs and different treatments. Pulmonary Rehab should be available to all lung patients in my opinion."

#### North Dakota: Becky A.

I am a hospital manager of a group that includes Pulmonary Rehab. As part of our work in reducing readmissions (HRRP), we evaluate and refer inpatients for Pulmonary Rehab. The evidence is clear that Pulmonary Rehab reduces hospital/ED admissions and improves quality of life. In our case, Pulmonary Rehab reduces hospital admissions by an annual average of over 50% when comparing hospital/ED admissions six months before the patient enrolls in Pulm Rehab to six months after the patient is discharged from Pulmonary Rehab. Patients with chronic pulmonary disease frequently have other comorbid conditions. We know that Pulmonary Rehab also has a positive impact on those conditions, including heart failure, diabetes, obesity, hypertension, depression, and nicotine addiction. Our patients consistently express their gratitude for the program and the impact Pulmonary Rehab has on their health, mental/emotional wellness, and their quality of life.

## North Dakota: Kris S.

I have been fortunate to participate in pulmonary rehab for about 14 months. There is no question that my life has improved since beginning this program. I am so grateful that

Sanford Clinic in Fargo, ND has this rehab available for people living in this area. I credit my physical and emotional well being to this life changing program.

#### North Dakota: JoAnn T.

Hi, my name is JoAnn Thorson and I am a respiratory therapist that works in pulmonary rehab in the state of North Dakota. I have seen many patients that come through our rehab make great strides in their strength and endurance but I want to share a story of one patient. Roger has severe COPD and MAC. He came to us wearing 4 lpm oxygen and very deconditioned. He started in our rehab and was very committed in his attendance and pushed himself all the time to do what he was able to do. He was able to lose some weight, increased his strength and endurance to the point of being able to participate in the Fargo marathon 5k. He walked the whole 5k carrying his oxygen tank in his backpack! This motivated him to continue exercising in rehab and he was eventually able to completely get off his oxygen. He eventually started to teach water aerobics at our local YMCA! Roger often stated that it was the structure and guidance of our rehab and staff holding him accountable to show up for exercise that helped him achieve his goals. Pulmonary rehab works in keeping our patients with lung disease healthier and independent as long as possible. We need to have adequate reimbursement for pulmonary rehab to continue offering this valuable service to our patients.

#### North Dakota: Elaine.

Pulmonary rehabilitation has really helped me. I can breathe so much better, and I can walk for 20 minutes now without resting and do all my other exercises. Before I started rehab, I couldn't walk from my kitchen to my bathroom without stopping to rest and the distance was only a few feet. I probably would be in a wheelchair now if I hadn't gone to rehab. It is really amazing how much it has helped me and I couldn't live well without it. Thank you for keeping the program.

#### North Dakota: Kaushik B.

I am a hospitalist taking care of COPD patients on a regular basis. In addition to that I'm also the Medical Director of the Pulmonary Rehabilitation Service here at Sanford Medical Center, Fargo, North Dakota. I have also practiced as a primary care physician for many years. Hence I have experience in taking care of COPD patients both in the ambulatory as well as inpatient setting. Throughout these many years I have seen both as a primary care physician and now has a hospitalist how my COPD patients are benefited by pulmonary rehabilitation interventions. It has helped them to have a smooth transition from an acute inpatient treatment, back to home and has helped them to stay away from being readmitted again. It has also helped them with their anxiety levels. I have seen in my patient's quality of life improve with pulmonary rehabilitation. There ability to exercise increases and thereby also have overall beneficial effect on their physical conditioning and in turn help improve their cardiovascular health too. Many of these COPD patients have also other comorbidities including cardiac conditions. The health data update by the pulmonary rehabilitation team goes a long way in assisting providers to treat cardiovascular conditions more effectively. Hence I think pulmonary rehabilitation is not only subjected to COPD management but has an overall beneficial effect on the patient's

health. It is such a common sense that this goes a long way in keeping our COPD patients healthy and out of ER and recurrent hospitalization. This also in turn goes a long way in saving millions and millions of dollars in healthcare costs as we all know that with the single admission into the hospital, healthcare bills can run into thousands and thousands of dollars.

I personally believe pulmonary rehabilitation is an excellent example of preventative healthcare measure. It is in the best interest of the patient, brings down overall healthcare costs and is hence it is in the best interest for the country as a whole.

#### Ohio: Daniel.

I've always been fit as a fiddle and a lifetime athletic person. What really has helped me big-time, is not exercise per se but losing and keeping off the fat ... now that takes guts! Fat-assed COPDers (I used to be one) find it more difficult to exercise at all and also all that visceral fat crowds out the person's internal space needed for those overinflated lungs to expand.

Still, think working out is weird and simply a fad of the times. My parents never even heard of a gym except for boxers. What I do instead, is just walk as often as needed. House cleaning is my exercise and my home is my gym. Half hours of vacuuming carpets 3 times a week ... buffing out the wood veneer kitchen flooring twice a week ... high-dusting for at least an hour weekly ... cleaning 4 toilets twice a week ... etc, etc

## Vermont: Caitlyn B.

My name is Caitlyn Boyd, DPT and I am the Pulmonary Rehabilitation Program Coordinator at Southwestern Vermont Medical Center in Bennington, VT. Pulmonary Rehabilitation at our facility began in January 2015. Our program runs for eight weeks and offers a morning or afternoon session two times per week. We treat up to sixteen patients at a time who have been diagnosed with a chronic lung disease. We also offer a supervised Maintenance Program after completion, where patients can continue to exercise at our facility for a small fee. As of June 2016, we had a completion rate by all patients regardless of diagnosis of seventy seven percent. Seventy percent of patients had a significant improvement on the UCSD Shortness of Breath Questionnaire, seventy four percent had significant improvement on the St. George's Respiratory Questionnaire for COPD Patients, sixty percent had significant improvement on the Six Minute Walk Test and Ten Meter Walk Velocity Test, and fifty one percent had significant improvement on the Bristol COPD Knowledge Questionnaire. Along with these functional outcome measures, we reviewed readmission data for patients diagnosed with COPD. Three months prior to the program, the admission rate for these patients was twenty one percent, on average. The readmission rate for the first three months after completing the program was eight percent. For those who entered the Maintenance Program, the readmission rate for the first three months after completing the program was zero percent.

# Vermont: John G.

## What is Pulmonary Rehabilitation?

 Pulmonary Rehabilitation is a program for people with Chronic Lung Diseases such as Emphysema, Chronic Bronchitis, and Interstitial Lung Disease.

## Pulmonary Rehabilitation Objectives

- Improve quality of life.
- Improve ability to manage their illness and health status.
- Restore the patient to their highest possible functional capacity.

## **Education**

- Disease Process
- Medications
  - What, Why, How
- Stress Management
  - Relaxation Techniques
- Energy Conservation
- Benefits of Exercise

# **Outcome Measures**

- Nine groups graduated through June 2016
- 76.8% of participants completed the program

# **Dyspnea Measurement**

UCSD (Shortness of Breath Scale)

 70% of graduates had significant improvement

## **Quality of Life Measurement**

St. George's Respiratory Questionnaire for COPD Patients

 74% of graduates had significant improvement

## Knowledge Measurement

Bristol COPD Knowledge Questionnaire

 51% of graduates had significant improvement

## **Function Measurement**

10 Meter Walk

 60% of graduates had significant improvement

# Readmission Rate for COPD

- Admission rate for the graduates three months prior to Pulmonary Rehab participation = 21.1%
- Readmission rate for first 3 months after graduation from Pulmonary Rehab = 7.9%

# Readmission Rate for COPD

 Readmission Rate for first 3 Months after graduation from Pulmonary Rehab in individuals who stayed in our Maintenance Program = 0%

## Wisconsin: Tanya E.

I am a customer of Apria Healthcare Oxygen. They also supply the medication for my nebulizer machine. This is not a letter to talk about one main problem but a bunch of them. Starting with how the customer services representatives treat me when I call. I have never had a nice representative in all of the eight plus years that I have been a customer. They act like it is just a job for them and don't really listen to you. If they could live just one day on oxygen and see how frustrated it is to get an answer to a question, they might start to get the idea. We did not choose to be on oxygen and don't want to feel like we are a bother. The second problem is with the oxygen department. I am currently on 10 liters and right now I have to deal with "E" tanks because Apria is getting out of the business of supplying liquid oxygen. To me that is not good news. The "E" tanks are heavy and last only 40 minutes or so on 10 liters. Shorter times for higher liters. Currently I am in rehabilitation and was provided with a liquid tank that goes up to 15 liters. I am on a schedule with the oxygen delivery department for every three months and every three months I have them take at least 15 out of the 25 that I have with them for they are empty and they bring in 15 more, but what would ever happen if I run out and can't get a deliver until my schedule date because they don't deliver to my area till then. Really? Here we have someone depended upon oxygen 24/7 and can't get it. At least with liquid I would be able fill up my tanks when needed. I keep getting the same answer, it is too costly for them to have liquid but from my point of view it is going to get more costly to keep your customers and to get more. One tank verse three plus when going for an appointment, one tank verse three when going out with friends, one tank verse three when just going out. I am sure you get the hint by now. The last problem I am having is with the proper equipment being delivered, mainly the nose cannulas and tubing. How hard can it be to send the right stuff? When asking for high flow tubing I should expect high flow tubing (with the letters HF after the model number). I just rec'd an order before my extended hospital and rehab stays and it was all wrong, not only that but my address is wrong, doctor is wrong, phone number is wrong. I am very lucky that the UPS gentleman knows me. How many times do I have to call to remind them about these changes? And what is with the limits on how much tubing or cups I can order. I take more than one nebulizer treatments with a different medication and these two can't be mixed together so I have to use two cups which leaves me one left and if they are supposed to be switched out every two to three weeks. I am stuck with none.

I have my routine and know what I need. Why is it so impossible to get my voice heard? Do they think that I sit at home all day long coming up with these problems? I belong to a facebook group called LivingWithOxygen and we have 235 members that would agree with me. Something has to be done. I would so much like to switch to liquid but am told no. No doesn't cut it anymore. Why can't people see that even though I wear oxygen, I can still be an active part of the community? I hate not going places except to doctor appointments and having to figure out how many tanks I need for the day. My brain stills works it is just my body that is a little bit rusty.