



# Second Wind

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## NEWSLETTER

May 2003

*PERF, The Pulmonary Education and Research Foundation, is a small but vigorous non-profit foundation. We are dedicated to providing help, and general information for those with chronic respiratory disease through education, research, and information. This publication is one of the ways we do that. The Second Wind is not intended to be used for, or relied upon, as specific advice in any given case. Prior to initiating or changing any course of treatment based on the information you find here, it is essential that you consult with your physician. We hope you find this newsletter of interest and of help.*

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Write to Dr. Petty; Bronchiectasis: [subscribe@perf2ndwind.org](mailto:subscribe@perf2ndwind.org); Restrictive disease; Smoking addiction; FEV<sub>1</sub>; "Healing and Exercise" by Ron Peterson; Expiration date

**D**o you sometimes jump ahead to read Dr. Petty's monthly newsletter before the reading rest of the Second Wind? We don't blame you if you do. To tell the truth, it is the first thing that we read also since our "Type A" editor gets his letter to us weeks, and sometimes months, in advance. If you haven't read this month's letter entitled "*Triple Jeopardy*", please do so now so that you'll understand the rest of this message.

Did you know that Dr. Petty is the father of pulmonary rehabilitation? Back in the early 1960's, he conceived an idea for helping pulmonary patients. He managed to get a government grant and completed the first group pulmonary rehabilitation program in 1966. It was successful beyond what anyone could have dreamed. Dr. Petty established methods and techniques still used in programs today. More importantly, he demonstrated the value of helping a condition previously considered beyond help.

Did you know that he is also responsible for the then revolutionary idea of home oxygen therapy? He tells some wonderful stories of using his jeep, back in 1965, to personally deliver oxygen to old miners living in shacks up in the mountains. Results were, again, so dramatic that he was able to convince government agencies to fund a large-scale study of oxygen therapy in COPD. He led this study and was able to show that oxygen therapy prolongs the life of people with low levels of oxygen in their blood. Even today, this study is considered a landmark...truly the foundation on which we use oxygen today. Since then, he has continued his fight to make oxygen available to those needing it here, and around the world. Dr. Petty has continued this battle for Medicare and insurance coverage of oxygen over the years. It has been a tough, never ending battle; portable oxygen reimbursement is his latest effort. He has published dozens of books (both for patients and for other lung disease experts) and hundreds of scientific papers. We could go on and on. Some day we will devote an entire issue to the accomplishments of this remarkable physician, though even that wouldn't be enough to cover all that he has achieved.

In spite of his international renown, Dr. Petty likes to think of himself as a “simple country doctor”, the friend of us all. (And yes, he *does* make house calls!) That kind of caring shows in his monthly letters about medicine and his philosophy of life.

Dr. Tom has been writing a monthly letter for the Second Wind since December 10<sup>th</sup>, 1985. That historic first letter to his “Friends” was published in the January 1986 newsletter and he has written one every month since then! Even when *we* missed a month, he didn't, which is why you sometimes get a Second Wind with two *Letters from Tom*. These letters are archived back to June of 1994 on our website. In order to read these classics go to our website at [www.perf2ndwind.org](http://www.perf2ndwind.org) and **click on the Dr. Tom Petty link**. Someday soon, we hope to have all of them, way back to January of 1986, available for you to read or download. They contain timeless words of wisdom.

As you know, Dr. Petty also serves as an invaluable member of the Board of Directors of PERF. His vast amount of experience and knowledge has helped to guide our efforts and achievements.

Tom Petty has always been there for us. Now, it is time for us to do

a little something for him. If you have read the latest letter on “*Triple Jeopardy*”, you know that he has written that he would “appreciate your care, your concern and your prayers during this difficult time.” I’m sure that he will have that much, at least, from all of you but would you do just a bit more? Send him a card or a note. It will mean so much to him and be a small way of helping to repay him for all that *he* has done for all of us. You can send your mail to

**Dr. Tom Petty**  
**899 Logan St., Suite 203**  
**Denver, CO 80203**

It will be delivered to the hospital, or to Dr. Petty when he is back in Denver recuperating and up to reading his mail.

We know that some of you are not strong on writing letters, or even cards, but do feel more comfortable on the computer. Would you rather wish him well by e-mail? His wonderful secretary, **Kay Bowen**, has offered to print out all of your e-mail greetings, put them in a scrapbook, and give this special book to him when he is back in Denver. Her e-mail address is [kbowen1937@aol.com](mailto:kbowen1937@aol.com).

*Let your message be among those Dr. Petty is able to read while recuperating from this major surgery.*

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PERF would like to send thanks to Hal Lichterman, Bill and Shirley Grindrod, and Charles Symens for their recent generous donations.

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**Vera** wants to find a way to get chest physical therapy for bronchiectasis on an outpatient basis, and other possible treatment options.

*The pulmonary rehab program, or the physical therapy department, of any hospital should be able to help you. However, you first would need a doctor's prescription and a physical examination to make sure that this is appropriate therapy.*

You might also ask your pulmonologist about entering a pulmonary rehab program or starting an exercise program. Postural drainage techniques are taught to patients who are bringing up large amounts of sputum; usually more than ½ cup a day. Use your bronchodilator before your postural drainage and stay well hydrated. It helps if a family member can go along to observe and to be taught percussion and vibration techniques for a chronic problem. There are several devices on the market, which some patients find very helpful for bringing up sputum. Ask your doctor or therapist if any might be of interest to you. As you can see, there are a lot of options out there.

Without knowing more about your condition, all we can do is suggest some general information. *Don't be*

*afraid to ask your doctor for information!*



**Do you have access to the Internet?** If you do, keep reading!

**While you have been able to read the Second Wind on the PERF website at [www.perf2ndwind.org](http://www.perf2ndwind.org) you now can be notified *immediately* when the most recent Second Wind goes on line. To get this automatic notification of the latest newsletter, or other hot news, send an e-mail to [subscribe@perf2ndwind.org](mailto:subscribe@perf2ndwind.org). Nothing else is necessary. With the link that will be sent, you will have the choice of reading it on line, just like any other Web page, of printing it out exactly as published by using the .pdf format, or of doing both. You may print as many copies as you wish for your friends or support group. Sign up today!**



**Allyson** writes that she has restrictive disease and wonders what we can tell her about it.

Unfortunately, there is little specific information that we can give you since there are *many* different types of restrictive disease. They vary from being of little consequence to being very serious. The late stages of pregnancy can cause restriction of the lung's expansion, as does obesity,

and for somewhat the same reason; restricted movement of the diaphragm. Wearing a very tight bra can cause a self-inflicted form of restrictive disease instantly cured by relieving the restriction. The old-fashioned corset of the last century caused well-dressed ladies to "swoon" from shortness of breath caused by their cinched in waists and tight corsets. (When was the last time you heard of someone swooning?) More serious are diseases such as asbestosis and idiopathic pulmonary fibrosis to mention just a few. It is very important that you communicate with your pulmonologist to find out your proper diagnosis! Once you learn that, you can be given more specific information about your problem and what you can do about it.



Did you know that about 10% of people who smoke are *not* addicted? These are the lucky ones who can quit cold turkey without any problems. The other 90% of smokers are doomed to suffer withdrawal symptoms unless they have access to the proper treatment. There are several easy tests to diagnose how addicted a smoker is, since the severity varies from individual to individual.



Last month you may remember reading "**Walden Pond on High**" by *Dr. Tom Petty and Ron Peterson*. The accomplishments and goals of Ron, a lung transplant patient, are so extraordinary that we asked him to write for our

readers a little more about how he achieved such remarkable success. Ron asked that we not change any of his story but we would like to make a few editorial comments.

FEV<sub>1</sub> stands for the forced expiratory volume of air that you blow out of your lungs in one second. It is a measure of your lung health. As you may know, Dr. Petty wants every one of you to “Test your lungs, know your numbers”. FEV<sub>1</sub> is the number Dr. Petty is referring to. Do you know what *your* FEV<sub>1</sub> is? Better than Ron’s was, we hope, because his FEV<sub>1</sub> of only 9% of predicted was barely compatible with life. He was very, very sick which makes his efforts to continue exercising so very remarkable. **Please put the stress on the word “his”, because Ron gives undue credit to some of the editors of the Second Wind. Mary in particular is very uncomfortable with all the credit given her.** Praise such as his is sincerely appreciated, but *it is Ron, and Ron alone, who deserves the credit for his amazing achievements!*

It is easy to give advice but not so easy to act on it! And we do understand and sympathize with all you on how very difficult it is to follow through with an exercise program.

Ron’s story is unique, as is he. We hope you are as impressed and as inspired by his history as we are.

## Healing and Exercise by Ron Peterson

I have been receiving the PERF Newsletter since 1995 and have an unusual story to relate which illustrates another benefit for those of us with lung disease who exercise regularly. Perhaps this story will encourage others to begin to exercise *today*, as it is never too late to start...

When I quit smoking on January 9, 1996 (2,632 days ago by my count, and I have counted every day), I replaced the negative habit of smoking with the positive habit of exercise.

I very quickly made fast friends with **Dr. Thomas Petty, Dr. Richard Casaburi** and Mary Burns and they all taught me many things about exercise. Mary Burns, however, gave me the best lesson when she suggested that it might be a good goal to walk 60 minutes a day, 7 days a week. In 1997, I was accepted into a lung transplant program and began waiting for a lung transplant.

I immediately accepted Mary's suggestion as my goal and slowly started to increase my exercise times. ***The day I quit smoking, I could only walk one minute, at a very slow pace, around the living room.***

**It took about a year but I made it to the 60 minute a day goal and I very seldom missed even one day.** I continued this pattern until the day of my transplant, December 12, 2000 at Barnes Hospital in St Louis.

I experienced many benefits from this practice of exercise. The most important benefit was to be able to survive until a donor lung became available. At the time of my transplant, my lung function, FEV<sub>1</sub> was measured at 9% of predicted. It took 6 liters of supplemental oxygen for me to maintain my oxygen saturation level at 90% as I walked on a home treadmill at a breakneck speed of 1/2 mile per hour for an hour. I generally walked as soon as I woke each day.

*On the day of my transplant, I walked an hour as usual and was called to the hospital at 10 pm that night. The transplant was over by 3 in the morning and I went to ICU but was able to walk 15 minutes four times*

*that day so that I did not miss even one day of walking.*

The first few days I walked with lots of tubes, dragging an IV bottle up and down the halls of the hospital. After two days, the doctors told me I was doing so well I could go home if I wished. I opted to stay two more days so I could learn as much as possible from the transplant team before leaving the hospital.

I was pleasantly surprised when the doctors came in on rounds on the 4th day after my transplant and told me I had healed faster than any of the previous 552 transplants in their lung transplant program.

Barnes St Louis is associated with Washington University and has the largest lung transplant program in the world. I was the 553rd person to be transplanted there, and the last one of the millennium.

I asked the doctors to explain why they thought I had healed so quickly and they said it was because I was in such good physical shape from all the walking I did before transplant. They likened it to the way a professional ballplayer in tiptop shape heals so quickly after an

injury that would sideline a normal person for 6 weeks.

We all know that those of us with lung disease are a long way from professional caliber physical shape, especially just before transplant with only 9% of normal lung function. However, I am certain that the reason that I was in such good physical shape was because I was fortunate enough to meet up with Mary and God gave me the wisdom to follow thru on her exercise advice. After all, Mary should know what she is doing with exercise and lung disease patients as she has been doing it for 25 years now and was one of the first health professionals to promote daily endurance exercise in a rehabilitation environment. She has been lecturing internationally on this subject for many years and is recognized as one of the world's authorities on pulmonary rehabilitation.

Thanks to you, Mary, for your long-standing exercise advice! Also thanks for your many years of helping those of us with lung disease. I am now 849 days post transplant and doing well.

These days, for maximum exercise I jog up mountains of 9,000 feet, still for an hour a

day, every day of the week. I am working up to climbing 14,000-foot mountains. Since there are 52 of them in Colorado, this should take me a couple of years or so and keep me off the streets. Even when I am traveling, I still exercise for an hour a day every day; currently I do a combination of walking, and jogging, and wind sprinting and I feel good every day.

Please understand that there is nothing special about me and all of us have the opportunity to attempt to meet Mary's suggested goal of an hour a day-7 days a week. I can assure you that it is a very worthwhile goal.

Now my goal is to live well for another 92 years-to age 150. And why not? I understand that the average life expectancy is now increasing at a rate of 7 hours every day.

Ron Peterson

April 29, 2003, Kerrville, Texas

Wow! What a story! Would anyone like to try to top that?

Please note that ***Ron's extraordinary exercise achievements started by walking only one minute at a time. Even when he walked an hour a day he was not able walk any faster***



**on the treadmill than  $\frac{1}{2}$  mile an hour.**

**You do *not* need to walk as much as an hour a day to improve yourself.** Ron was aiming for the ultimate. You do *not* need to be an Olympic sprinter to achieve success! That being said, however, we are sure that no Olympian ever worked any harder, or had more true grit, than Ron Peterson. Ron, we salute you. It is an honor to be considered one of your friends. ♥♥♥

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**Have you noticed that your new label has “expiration”** and a date after your name? We finally are able to automatically keep you informed of when your subscription to the Second Wind expires. (Thanks to those of you who suggested this!)

The date you see listed is ***one year after the last time we heard from you.*** Some of you may be surprised to see that was several years ago. We really do need to hear from you once a year.

**If your expiration date has passed today’s date,** please let us know if you still wish to receive the Second Wind by regular mail. If you *do* want it mailed to you, there are two options to renew your mailed subscription. Write to

**PERF  
PO Box 1133  
Lomita, CA 90717**

and enclose a \$20.00 check made out to PERF to help us meet our expenses.

OR, if you cannot afford the \$20.00, send us a note saying that you wish to continue receiving the newsletter. We wish to continue sending it to anyone that benefits from it, regardless of ability to pay.

If we do *not* hear from you we will assume that you no longer wish the newsletter, or that you are getting it by e-mailing [subscribe@perf2ndwind.org](mailto:subscribe@perf2ndwind.org).

As you know, we do everything that can to save money and use it efficiently and where it is needed most. We do not want to waste donated money by sending the newsletter to those who may not want it. Thank you so much for your help in streamlining our mailing list!

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*All of us in the PERF family send our prayers and best wishes for a speedy, and uncomplicated recovery to our colleague and our friend, Tom Petty.*

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