Heidi Bonner went from being on a lung transplant wait list with 16 per cent lung capacity in January 2008 to having a healthier, high quality life through exercise and diet. She now is active in supporting others suffering from lung disease get back in shape.

“I’ve taken a depressing disease and turned it into a positive lifestyle,” Heidi says. To give back to others suffering from COPD she helps with the running of a Better Breather’ Club in Maple Ridge, BC.

Heidi smoked for 40 years and wishes she had quit earlier. But when she started, she said, there was no information about the harmful effects of smoking. In fact, ads in magazines had doctors endorsing different cigarette brands and charming babies posing in cigarette ads.

“We really didn’t know in those days what it would do to us.”

About five years before diagnosis, she started getting sick several times a year. She would be in and out of hospital with lung problems up to 10 days at a time. She couldn’t walk across the room any more. She was taken into hospital once again, and this time doctors didn’t know whether she would live very long.

After a battery of tests, including the 6 minute walk test, her lung capacity showed she had 16 per cent.

“You feel like a fish out of water when you are gasping for breath,” Heidi says. Finally she concluded that “there’s gotta be more to life than this.”

When she was put on the lung transplant wait list she was also put through a series of tests to determine if there were any other potential health problems.

She also started getting into shape, thinking that if she underwent major surgery, she would need to be in the best condition that she could.

She was able to quit smoking using a new drug at that time, Champix. After six months of tests, exercising, not smoking and eating well, she was told that her lung capacity had risen to 34 per cent and they no longer felt she needed a lung transplant.

Heidi’s highly motivated to keep herself in shape. Says she plans to live a lot longer than the five years they projected with a lung transplant. She continues to do the things she enjoys like cooking and making stained glass works of art.

Heidi two granddaughters live down the street from her and she has made a mirror for one and a stained glass window for the other. She cuts and solders the pieces in her living room.

As part of her new lifestyle she has also changed her eating habits. She says she is really learning to enjoy foods that she never ate before.

Heidi's highly motivated to keep herself in shape. Says she plans to live a lot longer than the five years they projected with a lung transplant. She continues to do the things she enjoys like cooking and making stained glass works of art.

Heidi goes to rehab three times a week and works out at home three times a week - she takes Sundays off!

Before she started getting into shape, Heidi said she would spend a lot of her time sitting on the edge of her bed watching TV.

Depression and isolation are very common for people with COPD because their mobility is limited by poor breathing.

Rehab and Support Groups are “key” to helping people with COPD live well with their disease.

Editor’s note: Sadly as most of us know there is a huge shortage of Rehab facilities in Canada. One of the things we need to push for in our letter writing campaigns!!
Amtrak Adventures With O2
Chris and Gwen Wigley, March 2010

Well folks for those of you who read our last COPD Newsletter, you know about the “Big Adventure” my husband and I had planned for this year. After our Caribbean Cruise with Sea Puffers, again with our great RT’s Celeste and Holly, who as usual took wonderful care of us, we decided to travel back from Ft. Lauderdale, Fl. to Seattle via Amtrak instead of flying.

Right off the bat I need to tell you that this is very doable, providing you do your “homework” ahead of time. We learned a lot and hope you can benefit from our experiences. One thing we learned that is invaluable, Amtrak Cabin Staff and the Redcaps are “Awesome”. They went above and beyond for us in so many ways.

To start our journey we took the train, day coach from Ft. Lauderdale to Tampa, where we were met by our COPD Canada Patient Network friends, Linnndie and Rich Stehm in Brandon. We had arranged to spend two nights with them before starting our journey home. We were met on the station by Linnndie, who had flagged down a people mover and a Redcap and Rich who had a cart for our luggage. Chris asked Rich how he recognized us and he said, “Well the portable oxygen was a good clue”! Wow, what a welcome we had, felt like family from the start. Drove back to their home where they had everything laid on for us. We could not have asked for more!! Linnndie had even provided some Neb ampules in a container in the guest bathroom, just in case Chris needed them!! We just felt right at home and like “family”. Wonderful relaxing time for two days and a chance to get our laundry done before the next leg of our journey! Linnndie and Rich even drove us in to catch a connecting bus for our next train, in Orlando.

The Orlando to Washington part of our journey was very much the first “learning experience” of our trip. Two people, luggage and a portable oxygen concentrator do not fit well in a “Roomette”. For day time the seats are comfortable and the view grand. Come night time when you are trying to fit one oxygen user on the bottom “bunk” and one slightly overweight, arthritic spouse in the “overhead” bunk would have made a really good comedy skit. Having boosted me up to the narrow envelope slit that was my night time abode, which took some ingenious manoeuvring, Chris then proceeded to try to get himself set up. Try to picture two facing seats pushed down into a single bed with about a one foot space between it and the door. After a few minutes of grunting and groaning, I peeked over my top bunk and saw my husband standing with one leg hovering above his bunk and one leg firmly lodged against the door, underneath the bunk and behind the Inogen concentrator which in turn was jammed up against the door between the bunk and the door. He looked a little bit like a whooping crane but I tried to look sympathetic and not laugh. He looked at me for a minute and said I think I’m stuck; you’d better open the door. Now you have to understand that I am only just recovering from the exertions of climbing up here, now he wants me to crawl down and open the door!! Greater love hath no wife; you know what I’m saying!! OK so we finally manage to hunker down for the night while wondering how the heck we are going to get out in the morning. Well we managed but we both agreed that when we got into Washington we needed to upgrade to a bigger “cabin” for the rest of our trip.

OK, Washington DC. Great lounge for travellers to wait in for the next leg of their journey. Along with our bags, we were escorted there on a carrier by a friendly Redcap. Nice lounge with comfy chairs coffee and refreshments. Chris spent half the morning on the phone with Customer Service arranging alternative accommodation for the rest of our trip. They were able to get us in a Handicapped room for most of the rest of the trip but only a Deluxe Bedroom for the next part of our journey to Chicago. We were in their hands so with some more cash and time, we were all set!!

Okay folks; our deluxe bedroom looked great until we were set up for the night and discovered that if you pulled the whole lower berth out to a double bed, you cannot get at the wash basin .Chris volunteered to sleep in the very narrow bottom bunk. So guess who was going up again. Yup that would be me!!

Night three, Handicapped Room. Folks with oxygen this is totally what you need. Much more room and if you feel you cannot make it to the dining car your Cabin Steward will bring it too you. Doesn’t get much better than this. Only downside is your travelling companion still, ideally would be extra skinny and very agile. That top bunk was a challenge folks, gotta tell you!! The thing is they set up the pillows at the wrong end. When you are climbing up to slide in you need to “swim to the right”. Pillows are set up to your left. It just doesn’t work unless you want your feet on the pillow!!

Anyway, we were now pretty much set until next stop Denver, where we were again meeting friends and staying over night. We met for lunch at our hotel with Roxlynn Cole and her better half Lou; Louise Nett, long time assistant of Dr. Tom Petty and Edna Fiore, Patient Advocate Extraordinaire were also there. What an interesting and informative meeting! We discussed Dr. Petty’s upcoming book “Adventures of an Oxiphile 2.”
After lunch Lynn Cole and Lou took us out to the “Oxyview” office to meet President Les Peterson and John Goodman of TTOT (transtracheal oxygen therapy) fame, who we had also met on our cruise; an awesome guy! [see article on Introduction to TTOT.] Not available in Canada right now but maybe in the future. Very interesting to meet with them and see the ongoing efforts to meet patient needs from a dedicated group of people.

From there we went on to American Medical Supplies where Chris was able to purchase a new Sequal Eclipse at a very competitive price. Unfortunately they are not able to ship to Canada but can certainly offer our US members a very good price or sell to a visiting Canadian; but you need to ask for a quote as they are not allowed to advertise prices and we can tell you they provide excellent service. If you have a “friend” across the border who could order for you and you pick up, that might be an option.

What a great day, back to the hotel for dinner with Lynn and Lou and a most enjoyable evening. Just another wonderful example of what a close knit group of friends we make through our Internet support groups.

The next lap of the journey took us through the Rockies and one of the reasons Chris needed the Eclipse as at these elevations his faithful Inogen was not going to be enough to keep his sats up. Wow; what an experience that was.

Just awe inspiring views that you just cannot begin to describe. We had a one delay due to a rockslide on the tracks and had to wait for that to be cleared. Glad they did before we ran into it. When we went by later, those were very big rocks!!

Next stop was Sacramento. We knew we had a long wait here but were not prepared for our first layover with no“lounge”. We had an eight hour wait and then we were told the was two hours late. Beautiful “historic” station but just wooden benches and a vending machine.

To our rescue came the Redcap who had brought us from the train into the station. He kindly offered when he came off shift to drive us to “Old Sacramento” so we could wander and showed us a really great restaurant for dinner.

Definitely again one of those “above and beyond” experiences that was common on our trip. The staff is wonderful and goes out of their way to help you. If you let them know when you check in you get help with your luggage and transportation to your rail car at each location and again from the train to the station at your stop.

From Sacramento to Seattle was uneventful and we spent the night in a nice hotel right on the waterfront. The next morning we took the “Victoria Clipper” a high speed ferry back to Victoria where our son was waiting to take us home. Tired and happy to be home but glad that we made the trip!
Introduction To TTOT - John Goodman, BS, RRT

The SCOOP program for transtracheal oxygen therapy (TTOT), has been developed and refined since its inception in 1986. TTOT provides you with a very safe and efficacious alternative to standard oxygen therapy using a nasal cannula. During this time, over 160 articles in the medical literature have proven the many benefits transtracheal oxygen has to offer. The information that follows, describes some of the major areas where documented benefits have been demonstrated and published in peer-reviewed journals.

Improved Mobility

Greater exercise capacity: Since transtracheal oxygen is delivered directly into the lungs, it is more efficient than oxygen delivered by nasal cannula. Transtracheal patients tend to be more active, and usually recover quicker from activities requiring exertion.

Reduced shortness of breath: Recent studies have shown that the flow of oxygen into the lungs, acts as an aid to breathing. This will vary from patient to patient, but many patients report they are breathing easier.

Longer lasting portable oxygen sources: Since most transtracheal patients reduce their oxygen flow rate requirements by 30 and 50%, your portable oxygen sources will last approximately twice as long enabling you to stay out longer, should you desire. TTOT patients can further extend their portable oxygen duration using approved oxygen conserving devices, including the new generation of POC’s.

Improved self image: Everyone likes to look their best. The SCOOP system eliminates the nasal cannula from your face, and the SCOOP system is easy to camouflage.

True 24 hour Per Day Oxygen Therapy

This is after all, the clinical objective of oxygen therapy. However, when doctors studied if patients actually wore their oxygen 24 hours per day, they found that the average patient could or would only wear their oxygen 17-18 hours per day. Any patient can tell you that it is not easy living with a nasal cannula. It is very uncomfortable and inconvenient. The SCOOP catheter eliminates the nasal cannula completely, and makes it possible to get your oxygen 24 hours per day, as prescribed by your doctor.

Elimination of the Complications of Nasal Cannula

TTOT eliminates the sore nose, ears, sinus problems, dry eyes at night, nasal congestion and runny nose associated with the nasal cannula. These complications make it difficult to wear your nasal cannula 24 hours per day.

Physiologic Benefits

Reduced red blood cell count: Some patients with chronically low blood oxygen levels have increased red blood cells, as the body attempts to compensate for the low oxygen levels. This causes the blood to get thicker and places a strain on the heart. TTOT can normalize this situation because oxygen is delivered on a 24 hour basis. It is simply the body’s way of saying, “I don’t need these extra red blood cells to transport oxygen any longer”. This in turn reduces stress on the heart in pumping blood throughout the body.

Improved blood flow through the lungs: When a patient’s blood oxygen level is chronically low, the small blood vessels in the lungs constrict. This in turn makes it harder for the heart to pump blood through the lungs. TTOT provides superior oxygen delivery on a 24 hour basis. This in turn significantly reduces the constriction effect, and thereby reduces the work load of the heart. TTOT can be of particular help in patients with Pulmonary Hypertension.

Improvements in oxygenation during sleep: Because the SCOOP catheter is never out of the windpipe, your oxygen will be delivered all night while you sleep, unlike the nasal cannula that can fall out of place at night. Many SCOOP patients report sleeping better on TTOT.

Decreased work of breathing: Because TTOT delivers oxygen directly into the lungs, it bypasses the nose, mouth, and nearly all the trachea (windpipe). This is called “dead space”. By decreasing the deadspace, many TTOT patients experience a reduction in their work of breathing (how much energy they must use to breathe). This can make a big difference in how mobile and active a patient can be.

Reduced Hospital Days

Several studies have documented reduced hospitalizations when patient hospital days are compared before and after starting TTOT. Hospital costs have also been documented to be decreased. This is probably due to the fact that patients are truly getting their oxygen 24 hours per day. This in turn is beneficial to other organ systems of the body such as the heart, kidneys, liver, and brain.

Improved Survival

A study done at a Denver community hospital involving over 160 patients, confirmed that TTO patients lived significantly longer (average of 24 months) than clinically similar (age, sex, lung disease, and lung function) nasal cannula patients.

As you can see, TTOT offers many benefits to patients requiring continuous supplemental oxygen. It is important that you discuss TTOT with your doctor. There are a few contraindications that must be evaluated, and ultimately the decision must be made by the doctor and the patient together. If you have any further questions, please feel free to call Transtracheal Systems at 800-527-2667, or visit our website www.tto2.com.

Editor’s Note: While TTOT is not yet common in Canada, some of our friends across the border may be interested in this alternative. Both my husband and I hope that it can be offered in Canada in the future. We met John Goodman on our travels and were very interested in the presentations he gave on our cruise with SeaPuffers.
**Rewarding Yourself**

The best part about being a good self-manager is the reward you will get in accomplishing your goals and living a fuller and more comfortable life. However, don’t wait until your goal is reached, rather reward yourself frequently. For example, decide you won’t read the paper until after your exercise. Thus, reading the paper becomes your reward.

One self-manager buys only one or two pieces of fruit at a time and walks the half-kilometre to the supermarket every day or two to buy more fruit.

Rewards don’t have to be fancy, expensive or fattening. There are many healthy pleasures that can add pleasures to your life.

In review, a successful self-manager

1. sets goals,
2. makes a list of alternatives for reaching the goal,
3. makes short-term action plans toward that goal,
4. carries out the plan,
5. checks on progress weekly,
6. makes midcourse changes as necessary, and
7. reward yourself for a job well done.

One last note:
Not all goals are achievable. Chronic illness may mean having to give up some options. If this is true for you, don’t dwell too much on what you can’t do. Rather, start working on another goal you would like to accomplish. One self-manager, who uses a wheelchair talks about the 90% of the things he can do. He spends his life developing this 90% to the fullest.

“Our greatest glory is not in never falling, but in getting up every time we do”. - Confucius

"A journey of a thousand miles begins with a single step." - From the quote by Chinese Guru Laozi
“Dr. Tom Petty left this world on December 12, 2009 knowing he was loved by many.” Louise Nett.

Before he died Dr. Tom set in motion and wrote the Preface and first four chapters of a new book. A further 16 contributing authors were invited to write a chapter covering their areas of expertise. Some of these are known to our members; Mark Mangus our “Ask the RT” on our website. Chris Wigley, Vice-President of COPD Canada Patient Network, Roxlyn Cole whose story was in one of our newsletters and John Goodman who has a featured article in this newsletter among many others.

Those close to Dr. Petty have worked hard to put all the material together to make sure it “went to print” even though he will not be here to see it.

To Preorder Adventures of An Oxy-phile 2

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http://www.drtompetty.org
oxyphile2@aol.com

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Can You Give Just a Little of your time, on line, by phone or by mail?

We really need more provincial representatives. The more volunteers we have the less time will be needed from you to donate. We are a few helping a lot and our membership is growing daily!! Please consider giving just a bit of yourself to help us to help others. We certainly understand and realize there’s situations or occasions when you simply can’t be, or aren’t, available. However; the more people we have, the more of a “pool” there is to draw from to help cover for others when they aren’t well.

Please consider volunteering just a bit of your time.

Contact@copdcanada.ca
**Laughter The Best Medicine!!**

![Cartoon of a dog and owner with a computer]

"I said SIT!, You Idiot!"

It's going to take me a little longer to answer my e-mails now....

---

**Healthy Eating**  
**Cod Cakes**

Box of chicken stove-top stuffing mix  
4 1/4 oz.

Water  
2/3 cup

Lemon juice  
2 tbsp.

Sliced green onion  
2 tbsp.

Grated lemon zest  
1 tsp.

Cod fillets, any small bones removed, coarsely chopped  
1 lb.

Bacon slices, cooked crisp  
4

Cooking oil  
2 tbsp.

Combine first 5 ingredients in large bowl. Let stand for 10 minutes.

Process fish and bacon in blender or food processor until finely chopped. Add to stuffing mixture. Mix well.

Divide into 8 equal portions. Shape into 3 inch diameter cakes.

Heat 1 tbsp. cooking oil in large frying pan on medium. Add 4 cakes. Cook for about 3 minutes per side until golden. Remove to large plate. Cover to keep warm. Repeat with remaining cooking oil and cakes.

Makes 8 fish cakes.

*1 fish cake:* 154 Calories; 6.8 g Total Fat; 11 g Carbohydrate; 1 g Fibre; 12 g Protein; 351 mg Sodium
### News & Views

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### REMEMBER
Please identify yourself as a COPD Canada Patient Network Member and ensure you have your membership number on hand when you contact these companies. For additional information on these and other items, visit our site at www.copdcanada.ca
Dear Readers,
I can’t believe it is almost three months since we last visited with you! Lots of adventures since then. Read about our Amtak trip on page 2. Had two wonderful days with our well known members, Rich and Linndie Stehm who gave us a fantastic welcome and were the “hosts with the most”. Also met with John Goodman of TTO fame, a fascinating man with a wealth of knowledge and information to share. Remember the interview with Roxlynn Cole and her TTO experience plus marathon fame? Well we spent a great day with her in Denver, also met Louise Nett, long term assistant of Dr. Tom Petty and currently helping with the publishing of his book “Adventures of an Oxyphile O2”. See our contact to preorder on page. Our own VP and my better half Chris contributed a chapter for the book and I think it’s pretty good! Could be a little biased do you think?! Don’t forget.

This is YOUR newsletter.

click all suggestions or comments to: gwen@copdcanada.ca
Sincerely,

Gwen

“And Heeeeeere’s Joey!!”

Checking out who the heck is using “my” space here guys??

Gwen & Chris’ visit to Linndie and Rich Stehm this March.
Newly Diagnosed?

If you've recently been diagnosed, and even if you browse no further, READ THE POINTS BELOW. But; above all remember...

You're NOT ALONE! and you don't need to feel like you are.

This is constantly be stressed throughout our website because when you first find out that you have COPD that's what you're undoubtedly thinking. (Remember: There's 750,000 "physician diagnosed" cases here in Canada and probably that many again "undiagnosed or "misdiagnosed."

There ARE Things You Can Do

Stop Smoking if you've not already done so. This will slow down the progression of the disease.

Ensure you have the latest and best meds for your disease symptoms. If you don't know what they are, do some homework, or ASK your Dr.

(Great advances have been made with medicines for help with the symptoms of COPD...i.e. Symbicort and Spiriva)

Take your meds regularly; not just when you're feeling bad. (It's like pain medicine....it's harder to get pain under control after the fact than it is to get a jump start on it)

Exercise; walk, walk, walk! Even if you can only go a few feet to begin. Do it again and add another step next time. (Reason: The more fit you are, the less demand or need you muscles have for oxygen. This means you'll function better with the day to day things.

If you've never been tested but are being treated for COPD, even asthma........ASK for a spirometry test. A PFT would be nice but start with the spirometry at the very least.

Ask for copies of your PFT or Spirometry reports for your records and keep them. Learn to interpret the test findings.

Avoid people with colds. Forget about embarrassing them. This could be the difference between life and death.

Keep your hands clean. Regularly wash with soap and water and do what many do; carry hand sanitizer and use it frequently when you're away from home. Your family must as well.

Avoid crowds; particularly in the winter months during the peak of cold and flu season. This doesn't mean you stop going out or socializing but simply means you should be more cautious. (Do you really need to go to that huge, crowded concert in the middle of January?)

Get a flu shot and a pneumonia vaccine. (If it's not offered or suggested, ask for it)

If you're overweight, try to loose some. If you're underweight try to put some weight on.

Try to maintain a social circle of friends you're comfortable with and get out if/when you can. If you're severely depressed and it lasts for an extended period of time....see your Dr. A mild anti depressant can make a big difference.

If you think you're catching something, if your mucus changes, or if you have increased shortness of breath or if you're coughing more; even if you're not "feeling" well....see your Dr. Don't wait. Forget about the concerns of being a hypochondriac. Things can change very quickly; especially after a recent bacterial infection.

Always carry your rescue puffer

Ask your Dr. about having an antibiotic on hand at home and under what circumstances or situations you should begin them. You must still get in to see the Dr asap.

Join us - we're patients helping patients
For those of us who have the disease we remember all to well the thoughts that raced through our minds. The biggest, just after being told we had this disease, was the thought of death and the feeling that we didn't have much time. However; there are many people who are, and have, lived with this disease for many years and coped quite well. But; to be one of the multitude, you have to become active and proactive when it comes to your illness.

Live, Learn and for Heaven sakes.......Speak Up! You must be your own advocate!
Too much responsibility and emphasis with this disease is placed on our family Dr.'s. They CAN'T be experts at everything and there simply isn't enough specialists to go around. Help them and yourself, by learning.

There's no reason for you to let this disease control your life; it doesn't have to be that way. With the right attitude, support network, efforts on your part, medicines and Dr., you can learn to control "it"!
**COPD Canada Patient Network Membership Form**

*Please fill in and mail, or go to the web address below for the online form.*

COPD Canada Patient Network  
Attn: Dave Raymer  
3047 Old Sambro Rd  
Williamswood, NS B3V 1E6 Canada

The “On-Line” Membership Form can be found at [http://www.copdcanada.ca/sign_up.htm](http://www.copdcanada.ca/sign_up.htm)

**Current Savings For Members:**  On;  Oxyview Eyeglass Frames, a Substantial Discount from GelFast (hand hygiene), Finger Pulse Oximeters, Medical Acoustics “Lung Flute,” flow meters, Stairlifts, Acapellas, SoftHose Cannulas, Hose, Cold Weather Masks and more!  [www.copdcanada.ca](http://www.copdcanada.ca)

_There’s no Dues or Fees. Membership is FREE._

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<td>As a member of the Network it is understood and agreed that if we undertake a mail campaign to legislators or other governing bodies of importance as it relates to COPD, that you will participate in this when the request to members goes out. Usually the Maximum is twice a year. <em>(The above is applicable to Canadian members)</em></td>
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