



News & Views

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In and Around Our World

Travelling with Oxygen - by Chris Wigley

I live on Vancouver Island, and as a member of the board of COPD Canada Patient Network, I have been a delegate on the interim steering committee of the Canadian 'Lung Health Framework'. That in itself is another story entirely, but it has meant that I have needed to travel three times from Victoria to Ottawa, and once to Vancouver.

As a patient with severe COPD and on Oxygen this means that I definitely need oxygen when flying. As you go higher the air becomes thinner and each breath you take in contains less molecules of oxygen. The pressure in a modern jet plane is the equivalent of an elevation of 8,000 ft (2,500 metres), so even some people who do not need oxygen at sea level, may need it when flying.

Living with oxygen always takes some planning, but a trip by plane and a stay for a week or so in another city takes a lot more than a visit to the corner store! Living in Canada is not always the easiest for those on oxygen, but where flying is concerned, it is truly much easier. This is because **WestJet** operates here, and they not only treat their passengers extremely well but they also fully recognise and allow for the needs of passengers on oxygen. They simply allow users to bring on board their own oxygen tanks (only on flights that do not leave Canada) or portable oxygen

concentrators!

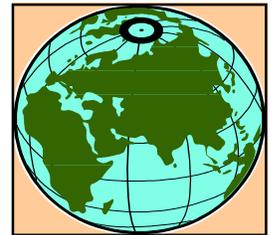
You are allowed up to two systems, which could be two tank systems (regulators may not be changed while on board the plane) or portable oxygen concentrator, but not liquid systems such as a Helios.

Planning also involves arranging for oxygen at your destination (I used Medigas in Ottawa, prescription for the oxygen needed but they obtained a copy from my local supplier), and a prescription from my doctor on a special form from Westjet [other airlines are likely to have a similar requirement].



I normally use a Caire Spirit liquid oxygen system, but this is not allowed for in flight use. So for my first trip I arranged to stay the night before at my son's house and then for him to drive me to the airport. The plan was to use the Spirit until I got to the airport to save on the Inogen batteries, then switch to the Inogen and keep my one cylinder (in a hydration backpack) as a backup in case the two batteries would not last the full time.

On arrival at the airport I



planned to pack my Spirit in my checked baggage and switch to my Inogen for most of the rest of the journey. Those of you who use liquid oxygen can probably imagine this next scene. To pack the Spirit in my baggage would mean that I would have to vent out the liquid oxygen from the Spirit. So there I am, standing outside the main door to the terminal, and I take my spirit and open the vent valve – clouds of white gas now surrounds me and the other passengers at the Departure entrance to the terminal. And the security personnel and RCMP start moving in!!!!

I am very lucky that my son, a civilian member of the RCMP, knew the RCMP officer and was able to explain that I was just venting some harmless oxygen. Otherwise I might still be incarcerated awaiting trial for terrorist acts! I really don't blame the check-in people, but they would not let me put the now empty spirit in my checked baggage! I think I was lucky even to get on that plane!

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About Clinical Trials & Studies

Our thanks to Scott Fulton, Research Co-ordinator with the Queen Elizabeth III Health Sciences Centre, Halifax, for the time he took to provide us with answers to some common questions on clinical trials, how they work, who participates and some background on the professionals who then conduct them.



Q. What's the difference between a Clinical Trial and a Clinical Study?

A. A clinical trial is a specific type of research study. It is the process that new drugs or devices go through prior to receiving government approval. The studies are conducted to ensure that the drugs are both safe and effective in treating the condition they are designed to treat.

Research studies cover a much broader area. They are designed to answer a question that the person conducting the study has in mind.

They include drug trials but also may include observational studies, genetic studies, etc.

Q. Are they usually safe?

A. Patient safety is the most important rule governing research. All studies conducted at a hospital must be reviewed and approved by a research ethics board [REB]. It is up to the board and the people conducting the study to decide whether any potential risks to study outweigh the potential benefits. If the risk is too great, the study will not be conducted. For example, it may be found that a side effect of a new drug is the increased chance of experiencing a headache but may also improve the overall quality of life for someone who has COPD. In this case the benefit out weighs the potential risk and the study would most likely be conducted. During the study, a subject's health is closely monitored by various medical tests to ensure their well being.

Q. How do you find your participants?

A. The type of research study we are conducting determines how we might find subjects. If we are finding subjects to test a new type of medication for COPD, we may ask some of the patients who are currently being treated by one of the investigating doctors. Other options would include putting up posters in the hospital, running newspaper/radio/TV advertisement or sending out a letter to some of the local family doctors asking them to refer people who might benefit from study participation.

Other studies might use random phone calls to ask people to participate, and sometimes we may just use a word of mouth approach.



Q. Who can participate?

A. Who can participate depends on the type of study. Each type of study has its own inclusion/exclusion criteria that determines who may go into the study. This could be as simple as an age limit or as complex as specific lung function measurements or a person's medical history.

Q. Why should a person participate in a trial or study?

A. Obviously I'm biased and think everyone should participate in research. Potential benefits include the opportunity to be followed very closely by a specialist and the potential to use a new medication or device before it is available to the general public.

One of the biggest benefits, in my mind, is the opportunity to learn more about your disease. During the course of a study, participants have an ample opportunity to ask questions they may have about their disease, including what treatments are available and what different tests mean.

Q. Does the individual get paid?

A. Typically a small amount of money is provided to cover the expenses of study participation i.e. parking, meals, gas, etc. It is important to keep the amount of money paid to a minimum to ensure people don't enter the study "Just for the money".



Q. Are trials and studies usually conducted in a hospital environment?

A. Although the majority of research is done through hospitals and universities, there are a number of family physicians or specific research facilities that also conduct research studies.

Q. If a patient doesn't see a specialist, how would they connect with a facility that conducts trials and studies and how would they even find out about which ones are currently being recruited for?

A. There are a few different ways to find out about research studies. There are several websites that list research trials being conducted in different areas. You may also see advertisements in newspapers/TV etc. Another idea would be to call the ethics board at your local hospital and ask them if they know of any studies being conducted in COPD.

Q. Can a participant drop out of the study or trial after it begins?

A. All research studies being conducted in the hospital are on a volunteer basis. This means that you always have the option of stopping study participation for whatever reason you want without it affecting your healthcare. In the interest of your health, the study doctor may request a final study visit to ensure your well-being but it is up to you whether you choose to attend.

Continued on page 3

About Clinical Trials & StudiesCtd.



Q. What is it you “officially” do?

A. My position requires me to be a “jack of all trades”. My background is in Respiratory Therapy which is obviously beneficial in conducting research in COPD, Asthma, Pulmonary Hypertension, etc. Before the study starts I prepare the submission to the ethics board consent forms, a summary of the study, etc. as well as prepare the documents that are submitted to Health Canada

and the FDA for our site. After the study receives approval, it is my job to find subjects that meet the criteria for study participation and book them in for their study visits. During the visits I conduct the study procedures spirometry testing, ECGs, etc. and record all the information/measurements obtained in a case report form. During the study I correspond with both REB and the sponsor to ensure the study is being conducted properly, Throughout the study I work very closely with the doctor who is in charge of the entire study. Ultimately the study doctor is in charge and ensures that the study is being conducted in a proper manner and that the participants are safe from a medical standpoint.

Q. How long have you been doing it?

A. As hard as it is for me to believe, I’ve been a research coordinator for eight years now.

Q. At any given time how many trials or studies are you overseeing?

A. The number of trials at any given time varies. At times I may have only two or three studies that require a large number of patients or sometimes as many as ten studies with fewer

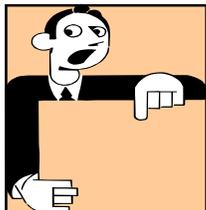
patients.

Q. Who usually decides which study or trial your facility will participate in?

A. Initially the study sponsor will send us a summary of the research they want to conduct. We review it at a research meeting with the rest of the respiratory staff and decide: 1 - If we are interested and 2 - If we have the subjects and resources to conduct the study. If we decide to conduct the study, we submit it to the research ethics board for approval. If they decide that it is okay to conduct it, then we go ahead.

Q. If a person has been in a trial for a new drug and it has proven that it works for that individual, when the study is over and prior to the medicine getting government approval to be marketed, can a patient continue on it?

A. The answer to this varies from study to study. In some cases, studies will have an on-going “open-label” extension where patients will continue to receive the medication until it receives medical approval assuming it appears to be working for them of course. This may not be the case for all studies and participants may return to their normal treatment regime once the study is completed. Normally what will happen at the end of the study will be discussed with the person prior to entering the study.



Interesting News in Pittsburg

The following report is from the Pittsburgh newspaper, The Tribune Review.

University of Pittsburgh researchers say they have made a breakthrough in the fight against chronic obstructive pulmonary disease ... the fourth-leading cause of death in the United States.

The Pitt pulmonary specialists report that they’ve found solid evidence that COPD is an autoimmune disease, and that it occurs when a person’s immune system attacks the cells that line the airways and air sacs of the lungs.

Patients are being enrolled in a clinical trial of an inhaled immunosuppressant drug called cyclosporine, that could lead to a better treatment.

“ COPD is responsible for 120,000 deaths in a year,” Dr. Frank C. Scirba, director of Pitt’s Emphysema Research Centre, said in a news release.

“ Available treatments, including inhaled bronchodilators, have little effect on disease progression. New information learned may help us to develop better treatments and perhaps even halt disease progression.

Scirba co-authored the study with senior author Dr. Steven R. Duncan, a professor in Pitt’s School of Medicine. The results, published in the American Journal of Respiratory and Critical Care Medicine, will be discussed at the International Lung Conference at the Omni William Penn Hotel, Downtown.

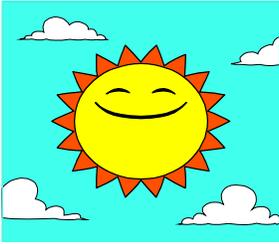
COPD is commonly related to smoking that diminishes breathing capacity over time and includes conditions such as chronic bronchitis and emphysema.

About 12 million adults have been diagnosed with COPD, with an additional 12 million unaware that they have the disease, according to the National Institute of Health. It is the second-leading cause of disability in the United States.

Patients with more severe COPD interested in additional information about the research clinical trial may call the Emphysema Research Centre at 412-692-4800.

http://www.pittsburghlive.com/x/pittsburghtrib/news/s_554721.html

Seasonal Hints From Ellen



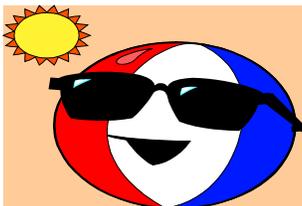
Sun Protection

The Canadian Dermatology Association suggests a 30 SPF, adding that going higher may not necessarily be better. People may think they are protected all day but in reality after a few hours sunscreen is either wiped off, sweat out or absorbed by the skin.

Apply an SPF or higher spectrum lip balm.

Wear a hat with a 7.5 cm [3inch] or wider brim. Hats with flaps that cover the back of the neck are also recommended.

Don't forget sunglasses.



Also make sure to keep well hydrated. Drink plenty of water especially if you have been sweating a lot..

Health Hints

* If you have a Car Starter and Air Conditioning, start your car a few minutes before you go out on those humid days.

* Vinegar to heal bruises Soak a cotton ball in white vinegar and apply it to the bruise for 1 hour. The vinegar reduces the blueness and speeds up the healing process.

* Quaker Oats for fast pain relief It's not for breakfast anymore! Mix 2 cups of Quaker Oats and 1 cup of water in a bowl and warm in the microwave for 1 minute, cool slightly and apply to your hands for soothing relief from arthritis pain.

* Sore throat? Just mix 1/4 cup of vinegar with 1/4 cup of honey and take 1 tablespoon six times a day. The vinegar kills the bacteria.



Gardening Hints

For a plant that needs a lot of water, sink a plastic bottle with holes in the bottom into the ground next to the plant. Fill this when you water and it will slowly soak the soil without waste.

Soak soil sporadically rather than daily. This encourages stronger roots to grow.



Member Discounts www.copdcanada.ca

Don't Forget to check out Special Member Discounts on our Website:

Substantial Discount gelFAST hand hygiene from Medonyx

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10% OFF

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Rose's Home Medical Specialties

Rose's offers our members a minimum of 10% OFF such items as Accapella Vibratory PEP therapy system

All contact made by email through eBay message system

Check our Website for details.



Answer to Cryptogram:
If at first you don't succeed try, try, again.

Caregivers Corner - "Bear's Story"



Editor's Note:

Barry Brooks is one of the Board Members for COPD Canada Patient Network.

Although this is an extreme, and perhaps unusual case Barry wanted to share his story with you, not to make you sad but to let you know that you are not alone and sometimes by sharing with others we can also ease some of our own pain. A caregivers role is one of the toughest there is and so often we forget that. Much as we want to keep our newsletter upbeat and positive for our members unfortunately life is not always fair or kind.

My late, wife died on May 26th 2002 from the ravages of lung cancer. We were married on October 27th 1962, so had been together for six months and 1 day short of forty years. A lifetime of memories some happy, some sad just like everyone else.

I had been retired for ten years because of medical conditions and we had both enjoyed Florida in the winters from November til April and our home in Ontario for ten years. As we were preparing to return to our home in Florida in the fall of 2000 we went to our doctors for a check up and to get six months supply of our medications to travel with for the winter. Everything went fine for me but when Anne went to her doctors the bomb was dropped. Her recent x-rays showed she had extensive lung cancer that was inoperable.

What a horrible, horrible blow to both of us. Our world was immediately turned upside down. The first and foremost worry was where to go. We had taken to this 6 months here, six months there lifestyle completely and rented out our home. We had a lovely trailer in a nice campground and the weather was turning colder. One of our sons came to the rescue by renting one of his apartments to us. The problem was it was a long way from Toronto.

We experienced every conceivable emotion possible. Guilt, anger, depression, feeling lost and abandoned. But the necessary steps were taken to get the help my wife needed. First was the terrible chemotherapy. This was given every three weeks in the Hotel Dieu in St. Catherines.

This was a terrible time for us as she was

so sick with the therapy. Of the three weeks between treatment she only felt good two days after and two days before. So in any twenty-one day period she was only herself for four.

A constant fight to be positive for me and just watch helplessly as my wife died before my eyes.

She lost weight, she lost her hair and the very worst she completely lost the will to live. That vital spark we all need to survive. You see she had lost her father to lung cancer and had watched and witnessed the same things that were happening to her. She dwelt in her misery so much so that all of our friends stopped coming and we were becoming more and more isolated from normalcy. The winter passed and then in the spring we moved back to our trailer. Then came the radiation therapy. We had to travel to Hamilton for this and because we lived so far away they let Anne stay for a week at a time for therapy. I would drive down to get her early Friday morning and return her on Monday. It was a godsend for me as she was fed and looked after all week long and gave me a much needed breather. Even though she was given all this chemotherapy and radiation treatments she continued to fade.

The words helpless and hopeless really do not really describe what happens. You just simply lose it all. Your life is put on hold and you just react to things. There was to be no more Florida in our future so we sold our house and bought a mobile home in a nice park. Our family home was still rented out. It was a wise move as it was all on one floor and was not too much for me to handle as far as keeping the place up.

Then comes the waiting and watching. Anne is now on oxygen 24/7 and eating less and less. Sleeping more and more, and just dwindling away.

As a last resort we went back to see a specialist in radiation in Hamilton and we were given the absolute brutal truth at that time. There was nothing absolutely nothing more that could be done.

There was no more chemotherapy, no more radiation could be given. She had been given the maximum dose that was allowable.

I will never, ever forget that interview. It shook me to the very core of my being. The tears I have kept buried are flowing again. It is so raw, the emotion.

He said, and I quote verbatim. "She will lose her appetite and not eat. But that is okay. She will lose her thirst and not drink. But that is okay. And finally she will lose the ability to breathe. But that is okay."

Dammit that is not okay. I cried all the way home and I still cry today.

The end result was that I just could not cope any more and put Anne into the hospital a week before she took her last breath. I was with her when this happened and that is what care givers do. The hardest thing of all was giving the hospital the DNR order. Do not resuscitate.

It is going to be six years soon and I have moved on. I have remarried to a wonderful woman named Carol and the shoe is on the other foot now. She is the care giver and sometimes I see the hard road ahead for her.

So a big thank you to every other care giver out there. It is not an easy job, in fact it is one of the very hardest jobs there is out there. But such a necessary one.

Humbly submitted, Barry (aka) bear.



Lung Health Framework Overview

report from Chris Wigley

In April I again represented COPD Canada Patient Network, in Jackie Whitakers place, at another meeting of the “Interim Steering Committee” of the Lung Health Framework. It is not easy to describe the LHF (Lung Health Framework) as it covers such a wide subject but at this stage I thought it would be helpful to give a broad overview and provide updates on progress as it occurs.

The work to date has been to come up with a draft document to improve lung health. It is intended to be used by everyone involved, from the Federal Government, the Provincial and Territorial Governments, Regional Health Authorities, University Research Departments etc. to help develop a comprehensive plans. It covers all lung diseases and tends to have a greater

emphasis on those often under-recognised groups such as Rural, Inuit, First Nations and Immigrant Communities.

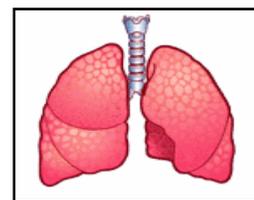
The Vision Statement is:

“Excellent respiratory health for all in Canada”

and the Mission is:

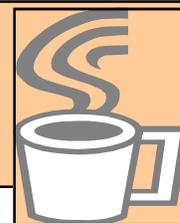
“To advance the respiratory health of all people living in Canada through collaborative and equitable patient care, policy, programming, research and leadership”

The Lung Health Framework is ready to move to the next stage: to define an implementation plan with timelines and process. At the April meeting, the ISC began to outline key considerations for an implementation plan and will assist in the development of a draft implementation plan over the summer. They will meet to review this plan in October. Further developments and or progress will be reported in future newsletters.



Healthy Drinking?

Green Tea Boosts Antibiotics for Superbugs
Information from HealthDay News 03/31/08



Green tea can help antibiotics be three times more effective in fighting drug-resistant bacteria, even superbugs, according to a study by researchers at Alexandria University in Egypt.

Green tea is common in Egypt, and it's likely that many people there drink it while taking antibiotics. Therefore, the researchers wanted to determine if green tea would decrease or increase the effectiveness of antibiotics or have no effect.

“We tested green tea in combination with antibiotics against 28 disease-causing microorganisms belonging to two

different classes,” Dr. Mervat Kaseem, of the university's pharmacy faculty, said in a prepared statement. “In every single case, green tea enhanced the bacteria-killing activity of the antibiotics. For example, the killing effects of chloramphenicol was 99.9 percent better when taken with green tea than when taken on its own in some circumstances.”

Kaseem and colleagues also found that green tea made 20 percent of drug-resistant strains of bacteria susceptible to a cephalosporin antibiotic, an important type of antibiotic, to which drug resistant strains of bacteria have evolved resistance. In almost every case and for all types of antibiotics they tested, the researchers found that

drinking green tea at the same time as taking the antibiotics appeared to increase the action of the antibiotics and reduce drug resistance in bacteria. In certain cases, even low concentrations of green tea were effective.

More information: The US National Centre for Complementary and Alternative Medicine has more about green tea.

http://www.everydayhealth.com/publicsite/ShowArticle.aspx?Issue=news/4/news614042.xml&dp=2008/03/31&q1=&cen=&xid=nl_EverydayHealthAshtmaandAllergies_20080401

Flying With Oxygen Ctd.

After that experience I just used the Inogen to get to the airport. I checked with Transport Canada (Canadian equivalent of the FAA) and with the head of the safety for Westjet and I now have a letter saying that it is safe to pack an empty liquid oxygen portable in checked baggage provided that the vent valve is kept open.

A total of about five hours flying time with at least one stop-over is really pushing it with only two batteries for the Inogen, and I would not have attempted it without the cylinder back-up. At the stops rushing to find an outlet to recharge the batteries between flights, and as you can't leave baggage unattended that meant only a quick visit to the washroom and no coffee (though I did once persuade the gate personnel to watch my bag for a couple of minutes. At times like this I find being on oxygen very limiting.

I was able to just slide the Inogen with it's wheeled cart and minipack for charger and spare battery, as well as the hydration pack with the M-6 cylinder under the seat in front of me. Still left room for my feet but hardly any room to even wiggle my toes!

In flight I used my oximeter to watch my sats and tried to maintain an SaO2 about 90%. This was fine although it needed occasional pursed lip breathing until I cranked up the flow rate as we ascended. However bending over in that confined space (and I admit to being a little overweight) to change batteries was pretty unpleasant. First

the concentrator shuts down, then you need to remove the battery, get out the spare battery, put away the old battery, put the new battery in and then re-start the concentrator all while bent double and with no oxygen just at a time when you really need at least a couple more litres/min than usual. Kinda makes bending over to tie up a pair of shoelaces seem like a walk in the park (actually even walks in the park aren't as easy as they used to be!).

The other thing that really caught me by surprise, and I think is something that has not been properly considered, is that there is less of a sensation of being short of breath than usual. I suspect that this is related to that lower pressure at altitude tending to help the body get rid of excess CO2 from the blood, and it is of course the raised blood CO2 levels above our own normal levels that drive us to feel breathless. It was really brought home to me when I glanced at my little Nonin after waking from a short nap and saw my O2 level had dropped to 80% . I do not have sleep apnea and did not have a problem maintaining 90% when awake and keeping an eye on that little Nonin. I really recommend a finger oximeter when flying.

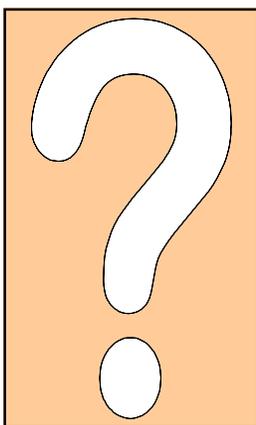
My other flight was to Vancouver by float plane. I love flying in small planes – you see so much more and there is more sensation of actually flying. This was on a small single engine Beaver (50 years old to the day when I made the flight!) owned by a

local air taxi firm. I wondered whether they would mind about flying with O2 but they knew what portable oxygen concentrators were and had no problem with my using my Inogen.

Although travelling with oxygen can sometimes be challenging, with good planning it is definitely doable and that can allow ones life to be much more satisfying. [Did I mention that two of my granddaughters live in Ottawa?!]



Puzzle Corner



Cryptogram

Are you a code breaker? How to Play: Each letter stands for another. Hyphens, repeated words, commas can all be hints.

Example: LDXWBTUDXC is
COURAGEOUS

The following is a saying:

AR BM RAWCM FDX QDSM CXLLUQ MWF, MWF, BEBAS!

Answer is on Page 4

And The Winner Is! My COPD Story - submitted by Linda Stehm



My name is Linda Stehm, I have been called Linn die all my life.

My story begins in 1984 when my husband was in the Military. We were stationed in Minot ND and I decided I wanted to fulfil my dream of becoming a nurse. I enrolled in Nursing school and did very well but then I began to have periods of extreme fatigue, the kind that never goes away. I was 5'5 and weighed 126 lbs. By my third semester I was down to 104 lbs. I passed out in the student union, and was brought to the hospital, and was admitted for tests. Two days later I was told I had Adenocarcinoma in my right lobe.

On Dec 14th 1984 I had my right lung removed and afterwards spiralled into a deep depression. However, I didn't realize at the time that I was suffering from depression. Three months later we lost our only son in a car accident. He was only seven years old. At this point I didn't care about too much at all and my one stress relief was to smoke.

One lung and I smoked!!

I look back and it seems unreal. I smoked on and off but finally quit in 1996. I was then told I had COPD/ Asthma. I had taken so much for granted with my health, always thought I was invincible. I blamed God, I blamed anything and anyone except myself. Eventually I learned I had to forgive myself and try to hang onto the rest of my life and make it count.

Now I love life. Everyday is a gift. I appreciate and treasure each day. Even the days that I am tempted

to complain about small things, I give myself a reality check. I think why me? Then I hear about so many other people, children young adults, the heroes dying in the war, and know what? My heart aches for other people in pain.

The things that help me are my family, friends and the wonderful COPD Canada community. I learned you can't go through life with two catcher's mitts on sometimes you have to throw something back.



The Station - by Robert J. Hastings

"Tucked away in our subconscious is an idyllic vision. We see ourselves on a long trip that spans the continent. We are travelling by train. Out the windows we drink in the passing scene of cars on the nearby highways, of children waving at a crossing, of cattle grazing on a distant hillside.

"But uppermost in our minds is the final destination. On a certain day at a certain hour we pull into the station. Bands will be playing and flags waving. Once we get there, so many wonderful dreams will come true and the pieces of our lives will fit together like a completed jigsaw puzzle. How restlessly we pace the aisle damning the minutes for loitering.....waiting, waiting, waiting

at the station.

"When we reach the station, that will be "it" we cry: "When I'm 18," "When I buy that new 450 SL Mercedes Benz," "When I put the last kid through college," "When I have paid off the mortgage," "When I get a promotion," "When I reach the age of retirement, I shall live happily ever after."

"Sooner or later we must realize there is no station, no one place to arrive at once and for all. The true joy of life is the trip. The station is only a dream.

"Relish the moment" is a good motto... it isn't the burdens of the day that drive men mad. It is the regrets

over yesterday and the fear of tomorrow. Regret and fear are twin thieves who rob us of today.

"So stop pacing the aisles and counting the miles. Instead, climb more mountains... go barefoot more often, swim more rivers, watch more sunsets, laugh more, cry less. Life must be lived as we go along. The station will come soon enough."



Letter From The Editor



Well what do you think so far? Is this helpful and/or informative? What could we do better?

We need to hear from you so that we can provide timely and truly useful information. So, if there are things you would like us to report on, research, or that you would like to share with others, lets us know? So far emails have not been overwhelming!!! so either we are doing everything right? or you don't think your opinion matters! We hope that is not the case. We really want to hear from you.

This is **YOUR** newsletter.

email all suggestions or comments to: gwen@copdcanada.ca

Sincerely,
Gwen

Sorry can't respond to any emails today,

Something has crashed on my computer and the mouse is missing.



