



News & Views

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In and Around Our World

“In the HOOD!” *by Jackie Whitaker*

Together We CAN
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Try to imagine waking up in an ICU unit, you're drugged, your vision's "not right", (or so you think); and you're staring out through what appears to be a thick piece of plastic or a window!

You then realize.... "There's something on my head!!! But what?"



The writer in the Helmet in ICU

Thanks to modern medicine, the last thing I remembered prior to "this" shocking awakening was being told I was intubated! I had felt the tubes for food and breathing, I knew the catheter was in, and when I went to lift my hand I realized my wrists were restrained and oh....the suctioning. I had actually smiled; it was like Déjà vu. Been there; done it..... But this???



CASTAR "R" Helmet with underarm straps. She looks better than me!!!

The more alert I became, the more I realized people were popping their head in (*no pun intended*) my unit and gawking. They also kept mentioning they remembered me "from before." "Uh huh" I thought. But what were they looking at even if I was familiar? What was wrong with me?" I didn't feel anything in my mouth.....

"What have they done now????!!!"

Finally! A nurse explained what was on me and that yes there would be quite a few people stopping by to "have a look."

Silly me; of course there would be; most hadn't seen this type of BiPAP before. But hey; they were in good company; I hadn't either and I STILL didn't know what I looked like! (*Not that it mattered; I was breathing on my own! ... sort of*)

I'd had an AECOPD (acute exacerbation of COPD) with two visits to the ER in 12 hours, multiple breathing treatments that weren't working, ABG's (arterial blood gas) draws depicting rising CO2 levels, (not to mention the stress on all my heart functions), failed BiPAP attempts; basically... a whole host of problems, got me where I was. Deep doo doo.... And I knew it going in to the hospital.

They did what they had to do to and for the 2nd time in my life, I was intubated and transferred to the ICU of another facility.

However, unlike my previous experience when I'd spent six weeks on a ventilator due to post surgical complications, this time was different. My breathing muscles were worn out, the meds needed time to work and my lungs needed to rest. I was exhausted.

A Bit About BiPAP & CPAPs

Thoracic medicine and medical



The Iron Lung

equipment developers have come a long way since the first modern ventilator of the 1930's – the Iron Lung; and although a few are still in use, they've given way to modern era ventilators.



Then, around 1980, they began using NIV (non-invasive ventilation) for COPD and by 2000 NPPV (non-invasive positive pressure ventilation) became the standard for acute exacerbations.

There's BiPAP and CPAP systems with masks of various configurations. Some are nasal, others oro-facial, (covering the nose and mouth). CPAP is quite often used for sleep/2

“In the Hood” by Jackie Whitaker cont’d....

apnea while BiPAP, though also used for apnea and those who can’t tolerate CPAP, is used more for lung and lung related diseases.

And the difference between the two machines even though they both supply positive airway pressure?

BiPAP supplies two levels of pressure rather than one; higher when the patient breathes in, and lower when they exhale. This is important because the patient doesn’t have to work as hard getting the air out. BiPAP can be adjusted as the patient’s need changes, while CPAP is constant and continuous; and only one level.

However; the masks aren’t without problems, especially when used for extended periods of time. Some of the negatives includes air leakage, facial pressure/sores, claustrophobia, nasal dryness, headaches, sometimes bloating from swallowing air; even indigestion. Or, if you’re like me, certain individuals simply can’t adapt or tolerate a mask of any type.

Getting back to ICU and the Helmet.....

It was Day 3 and they felt I could be extubated. However; things don’t always go the way we hope and after any extubation a patient may require ventilatory assistance or re-intubation. Yeahp; turned out that was me! Well; almost..

They extubated and I quickly became short of breath, wheezy, congested with no improvement from the meds. I was in respiratory distress again. Standard BiPAP wasn’t an option, and intubation is always a last resort.



Hmm; what to do...

But; the Gods were with me this time in the form of a Doctor I refer to as McIvor (*not his real name*).

I was told later that he yelled, “Bring the Helmet; this is a great opportunity to try it!” A few of the staff had just recently been trained on a similar unit although they’d never used one on a patient. They had only one Helmet on hand and just my size! Medium (*They come in different sizes including Pediatric*)

Though barely conscious, I was aware of 2 sets of hands pulling this elastic type of band over my head, down to my shoulders. After “hooking me up” and inflating the hood with oxygen, another problem apparently arose. Air was leaking out around my old tracheostomy scar. You see the bulb used to pump up the collar was missing. My husband (Dave) suggested they just put a bandaid over the indent in

my neck but Dr. McIvor grabbed a huge syringe, filled it with air and injected it into the collar. He repeated this process until it was inflated. Within 10 minutes Dave said I was smiling and giving the thumbs up!

Made by StarMed, the Castar R Helmet is BiPAP and CPAP and used for non-invasive pressure support. Developed in Europe, it’s light, latex free and single patient use. It has a built in neck/shoulder cuff



The Inflatable Collar

(collar) which can be inflated to help prevent air leakage with comfortable (and seamless) under arm fastening straps to help hold it in place. Although it can be loud (as can full face BiPAP masks) ear plugs were suppose to come with it. They didn’t, and thankfully Dave, brought a set in.

You can talk, though it’s hard to be heard when it’s running full out unless you’re able to yell (and that wasn’t an option with a very sore throat) Again, the other Dr. McIvor in my life, my hubby, used a stethoscope to hear me.

You’re able to move your head around inside, get oral meds, breathing treatments or drinks



The Patient Port

of water (unless you’re on a feeding tube in which case there’s a port for that too) and; in the event the pressure fails, it’s fitted with valves that automatically open. *Or just unscrew the patient port.*

After starting the “weaning off” later in the day, I was transferred the following afternoon to the step down unit in the hospital where my adventure all began. Because I was still paranoid about my breathing, I had one more night on the machine..... by my choice.

However, I did find that evening that it got a bit stuffy and my nose was very plugged. Perhaps it had already been that way and now that I was more alert, I was aware of it. I don’t know. But; having someone open the patient port for a minute so that I could turn my head to get a whiff of room air and a sip of water, helped greatly. Of course the night staff were nervous and unfamiliar with the Helmet and tended to avoid me unless one of my monitors came off or I beeped them.



The Helmet was only approved in Canada in 2004 and though it’s been studied, compared, written up and will continue to be so by various medical professionals for some time to come, I thank that German born Dr. McIvor and I thank the makers of this new piece of equipment.

You saved my Canadian Bacon!!!

On a final point, and a negative I suspect from a hospital standpoint, and from what I can ascertain, the Helmet can cost twice as much as a BiPAP mask.

Another six days; without the Helmet and I was released for the real work to begin..... Recovery.

And where is this unit now?

Where it should be; at home with us!

Believe me it goes with me from now on to the ER; even travelling. As for the Bulb for pressuring? My own Dr. McIvor (hubby), attached one from his BP cuff.



My own personal Helmet

If you would like to learn more about the Castar R Helmet and/or maybe even share with your Dr., please visit the following.... http://www.tmm.com/Catalogue/SellSheets/S28_INFO_NIV%20CASTAR%20R_ENG.pdf

A Case Report on Prolonged Use: <http://journal.ics.ac.uk/pdf/0902154.pdf>

There’s also a very excellent short video on You Tube. After all, a picture says a thousand words! <http://www.youtube.com/watch?v=ikCgKn8r7to>

Ask The RT ~ Mark Mangus, Sr., BSRC, RRT, RPFT, FAARC



Q. Oxygen, Ventolin Affects - 6 Min. Walk Test

While sleeping and exertion my oxygen normally falls below 90. This was decided in March after a 6 min. walk and a take home sleep & apnea test. Yes, I also have mild apnea. I saw a pulmonologist for the first time a few months ago. I blew, had ventolin and blew again. No change in those numbers. They did not do a 6 min. walk test.

Yesterday I saw the visiting RT again. I blew, had ventolin and blew again. No change in #'s. Then he had me do a 6 min. walk test. Half-way thru my chest started to hurt and I had to slow right down. However, my oxygen only dropped to 90.

I quit using ventolin a few years ago when I thought it wasn't working anymore for SOB. But was it working for oxygen and I just didn't know it?

Just a few hours before this I got SOB taking out the garbage and checked my oxygen. It was 82. So, it must have done something since I didn't take anything else before seeing the RT. I didn't think it was working as an emergency inhaler but it must have been doing something for the oxygen. Can you explain this?

Thanks Mark. Sandy

A. Hi Sandy,

I can't tell you definitively that the Ventolin had a direct effect to raise your oxygen level during the 6 minute walk done by the RT. I would wonder if (1) you actually observed the number the RT recorded? Was that day a "good day" compared to those when you are observ-

ing the low saturations. When you see the low saturations on your own monitor, are they "stable readings? In other words, have you given the monitor enough time to give you measurements that are consistent and not taken within say, 30 seconds of starting your measurement period?

Generally speaking we DO NOT expect for drugs such as Ventolin to have ANY effect on oxygenation except in some extreme instances like asthma where there is hypoxia due to very shut down airways that suddenly open up and after which the hypoxia is quickly corrected. But, without any response to the bronchodilator evident on your PFT, there is no reason to believe that anything like I just described would be at play.

Shortness of breath can result from BOTH or EITHER hypoxia or simply being in bad shape and having a very low FEV-1. As you did not say WHAT your FEV-1 was on any of the tests you had done, I cannot comment further in your situation. You cannot extrapolate so much from your observations, at least not to apply to your situation those few years ago. And, I am doubtful that the Ventolin is responsible at this time. There are too many other possibilities that are more likely. But, I simply cannot put a definitive finger on anything with the information you have given me. It is not enough information nor the pertinent information. AND the necessary information may not be available or apparent to you.

My bottom line to you would be to keep measuring your saturation under exertional conditions and if you continue to notice drops like that one to 82 %, badger your doctor until you get a proper walk test to verify or dispute your findings. If you ARE dropping like that, you SHOULD be given supplemental oxygen for exertion. Lastly, what did the sleep saturation study show?

Best Wishes, Mark

Q. The Accuracy of Chest X Rays in Diagnosing Emphysema

My question involves a chest x-ray and the diagnosis of emphysema. It appears from the medical literature that a chest x-ray can be used to diagnose moderate to severe emphysema but is not very useful in cases involving early or mild emphysema. Can you share your thoughts on this? Some of the radiology sites that I have visited conclude that lung changes are visible on standard x rays for certain stages of emphysema and even chronic bronchitis. It is difficult to find a consensus however. Thank you. John

A. Hi John,

Indeed, chest x-rays can show lung changes of chronic bronchitis and emphysema. BUT, what they show cannot be used to "quantify" one's disease, or assign severity. CT scans, as radiological studies are VERY sensitive to identify changes associated with COPD and the specific ailments under that umbrella, among other types of lung conditions. But, THEY cannot adequately correlate to "clinical condition and severity". PFT's are the most sensitive to correlate with clinical severity and even they are not 'sure-fire'. BUT, combine PFT's with clinical complaints and symptoms as well as a well-done walk test, and you have perhaps the best combination of information you need to effectively classify someone AND to treat them optimally. CT's and chest x-rays are helpful "after" those I just mentioned to round out the whole picture. My 40 years dealing with all these modes and mediums has brought me to that position.

Best Wishes, Mark

Do you have a question for Mark?

The form can be found on our website at

http://copdcanada.ca/ask_the_rt_your_COPD_question.htm

Laughter The Best Medicine



LIFE BEFORE THE COMPUTER

- * Memory was something that you lost with age
- * An application was for employment
- * A program was a TV show
- * A cursor used profanity
 - * A keyboard was a piano
 - * A web was a spider's home
 - * A virus was the flu
 - * A CD was a bank account
- * A hard drive was a long trip on the road
- * A mouse pad was where a mouse lived
- * And if you had a 3 1/2 inch floppy
...you just hoped nobody found out



Hold for a count of five.



Announcements!



➡ Our COPD Helpmates & Breathing Buddies Forum is NOW OPEN and seeking members. This is a closed forum (not open to the public or patients) . The Administrator is Mary Cunningham (the widow of a former COPD patient and member) She's looking forward to meeting you! <http://copdhelpmates.proboards.com/index.cgi>

➡ Have YOU mailed your Rehab and World COPD letters yet? If not, please check the last monthly AIR Mail for copies you can personalize.

Misplaced it? Send us an e mail to contact@copdcanada.ca and we'll forward them to you!

Relaxation Exercises

Why are they necessary?

- When we are stressed, we have “tight” muscles. These muscles are using more oxygen and making carbon dioxide.
- When we are short of breath, we become frightened. This causes our body to defend itself [“fight or flight”]. Your heart beats faster, your mouth gets dry and your body wants to breathe faster. We must turn this system off because it is making your breathing more difficult.
- When we do something that makes us so short of breath that we get scared, we tend to stop doing that activity. Stopping the activities causes us to become weaker and even simpler activities make us short of breath - it is a continuous “downward” cycle.
- Simply, if you want to remain active, it really helps to learn to relax.

MUSCLE RELAXATION

1. Sit or lie down.
2. Tighten the muscles in your toes and feet as tight as you can.
 Hold for a count of five.
 Relax the muscles.
 Feel the relaxation.
3. Tighten the muscles of your left leg.
 Hold for a count of five.
 Relax the muscles.
 Feel the relaxation.
4. Tighten the muscles of your right leg.
 Hold for a count of five.
 Relax the muscles.
 Feel the relaxation.

Cont'd Next Page

Relaxation Exercises Cont'd

5. Tighten the muscles of your tummy and “bottom”.

Hold for a count of five.

Relax the muscles.

Feel the relaxation.

6. Tighten the muscles of your chest and back.

Hold for a count of five.

Relax the muscles.

Feel the relaxation.

7. Tighten the muscles of your left arm.

Hold for a count of five.

Relax the muscles.

Feel the relaxation.

8. Tighten the muscles of your right arm.

Hold for a count of five.

Relax the muscles.

Feel the relaxation.

9. Tighten the muscles of your neck.

Hold for a count of five.

Relax the muscles.

Feel the relaxation.

10. Tighten the muscles of your face.

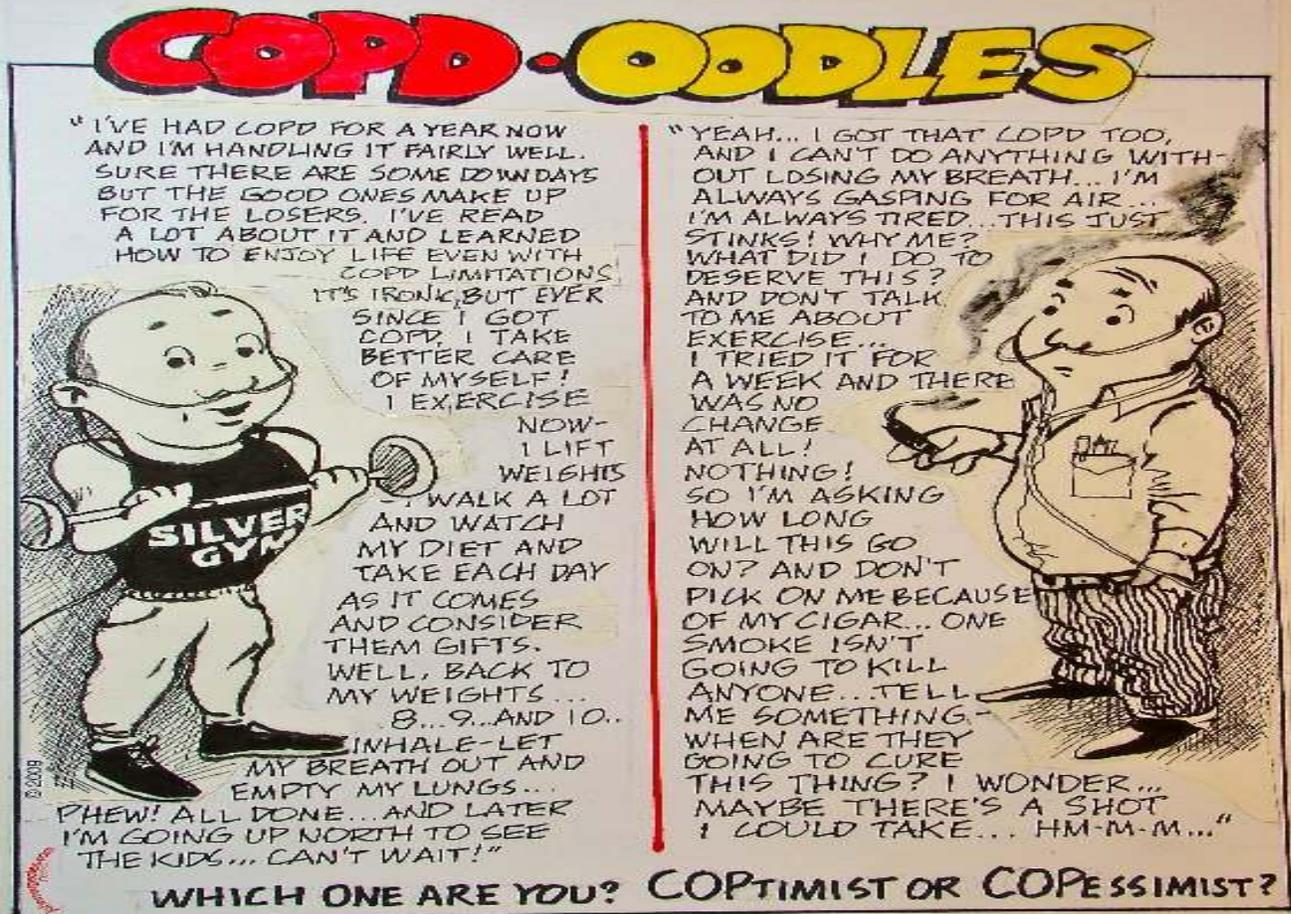
Hold for a count of five.

Relax the muscles.

Feel the relaxation.

Editor's note: Please try this with an open mind. Truly it will help!!

Food For Thought!!



We are not sure where this originated but our appreciation to the creator for an excellent example/comparison!!

Healthy Eating for COPD'ers with Diabetes

Pineapple Pork—This flavourful, mildly sweet pork is delicious over brown rice.

Lean boneless pork loin, trimmed and thinly sliced	3/4lb
Canola oil	2 tsp
Paprika	1/2 tsp
Ground ginger	1/2 tsp
Freshly ground pepper, sprinkle	
Medium carrots, thinly sliced	2
Medium green pepper, cut in large slivers	1/2
Medium red pepper, cut in large slivers	1/2
Small onion, sliced lengthwise into wedges	1
Can of pineapple tidbits, drained, juice reserved	14oz
White vinegar	2tbsp
Brown sugar, packed	1tbsp
Reserved pineapple juice	1/4 cup
Low-sodium soy sauce	1 tbsp
Ketchup	1 tbsp
Cornstarch	2 tbsp

Sauté pork in canola oil in a large frying pan for 1 minute. Sprinkle with paprika, ginger and pepper. Sauté until no pink remains in pork.

Stir in next four ingredients.

Reserve 1/4 cup pineapple juice. Set aside. Add remaining juice and pineapple to pork mixture. Drizzle with vinegar. Sprinkle with brown sugar. Stir. Bring to boil. Cover. Simmer for 30 minutes until carrot is tender.

Combine remaining ingredients in small bowl until smooth. Stir in pork mixture. Heat and stir until boiling and thickened. Makes 5 1/4 cups. Serves 4.

1 serving: 274 calories; 7.5g Total Fat [1.9g Sat. 49.7mg Cholesterol]; 279 mg Sodium; 20g Protein; 32 g Carbohydrates; 3 g Dietary Fibre

CHOICES: 1 Fruits; 1 Vegetables; 3 meat & Alternatives

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 add'l information on these and other items, visit our site at www.copdcanada.ca

Letter From The Editor



Dear Friends,

This month you will find a little less “content” from me in your newsletter for which I apologize. As many of our members are aware my husband and I are going through a challenging time. He has recently been diagnosed with esophageal cancer on top of his COPD and heart problems so we are trying to keep our heads above water, so as to speak, while he undergoes both Chemotherapy and Radiation treatment. However, I receive so many wonderful emails from you, our members, on the importance of this newsletter to you and I want to let you know how much that means to me. It certainly keeps me motivated to keep going!! I also need to let you know that although my husband was not a candidate for surgery because of his COPD and heart issues, because he has focused so much on keeping fit in spite of his problems, this has made it possible for him to be eligible for other options. As fellow COPD’ers you need to know that keeping yourself active and as fit as you can is HUGE!! If the Oncologist had not realized that in spite of his health problems, he had managed to keep himself active and as fit as possible, he would have not had too many choices!! Please keep yourselves as active as you possibly can. It makes a difference!!!!

This is **YOUR** newsletter.

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

Sincerely,

Gwen

Birdie Hypnotist!!



ICANHASCHEEZBURGER.COM

Talking to Your Dr

Having trouble breathing a bit?

- Maybe when you're walking or exercising?
- Do you cough?
- Do you wheeze? Is it waking you up at night?
- Are you, or were you a smoker?

For any of the above you're doing the right thing; seeing your Dr.

Did you know that in the province of Nova Scotia GP's are reimbursed less for a regular office visit than what a person normally pays for an oil change? (adjusted - after overheads i.e. nurses, phone, heat, benefits etc. Out of that re-imburement all of their overheads have to be covered.) It only stands to reason that they need to see more patients on a daily basis to earn a living.

Maybe it's worse in YOUR province.

The reality is: *They're not Gods*, they're *not experts in every field*; they can't be. Sometimes it's more like a "Jack of all Trades". So much emphasis is placed on them. Too much. Quite often they're simply facilitators. Then there are those.....well; you know which ones..... Please; help yourself by helping them and make the most of your visits with a checklist of questions. It's even better if someone is with you and can jot down the answers.

So; before you go....

- Make a list of your symptoms and how long it's been going on.
- Jot down your medical history and that of your family's and take it with you.
- Make a list of current medicines you're taking and the frequency. This also includes vitamins.
- Jot down ask any questions you can think of.

NOTE: During your first visit, if the Doctor feels it might be COPD, or perhaps asthma, and especially if you're given any type of breathing medicines (i.e. the Blue Puffer), if he/she has not suggested a Spirometry or Pulmonary Function Test, ASK for it! It's a simple, painless non-invasive breathing test.

O.K..... You've had your breathing tests and the results are now in and you've been called for a follow-up visit. The bombshell gets laid. You have COPD!!! If you're familiar with the disease you may not hear or remember a whole lot more. There are those who say you should ask questions at this point but it might be wiser to give yourself a few days to get over the initial shock before you sit down again.



Either way, chances are you're going to be put on meds to help you breathe better. On the next page is a list of things you may want to ask about during that 2nd consultation or your next visit.

Visiting your Dr. Cont'd

- Please explain the test results and what they mean.
- What exactly do I have and what stage am I?
- What treatments are there? What do they include, and do? Are they the latest medicines or treatments?
- (If you're on Disability)....ask if the medicines are covered. If no; ask how you/he or she/ can get them covered
- How often and how should these medicines be taken?
- What can I expect from these medicines or treatment? When will I notice a change?
- Are there any side effects?
- What can I do to slow things down ?
- Is there anything I should avoid or need to change while taking these meds or treatments? (This may include your current meds for an unrelated illness.)
- Can someone teach or show me how to use my medicines properly?
- Under what circumstances do I need to call you?
- When can I get a flu and pneumonia vaccine?
- When should I see you again?
- If I can't reach you, what do I do in an emergency?
- Will you prescribe antibiotics for me to have on hand at home? Under what circumstances do I begin them; better still.....Would you fill out an Action Plan for me? (You can print off a copy at the Canadian Thoracic Society's Website at http://www.lung.ca/pdf/1408_THOR_ActionPlan_v3.pdf –you'll need 3 copies of it, front and back)
- Do I need, or would I benefit from a rehab clinic? If yes; will you be recommending it? When can I expect to get in?

And REMEMBER.... You ARE NOT alone !!!

Together We CAN!

Care..... Advocate..... Network

Join With Us & Have a "Collective" Voice!



COPD Canada Patient Network Membership Form

Please fill in and mail, or go to the web address below for the on line 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

Contact Info: E Mail Contact@copdcanada.ca or Membership@copdcanada.ca
 Our Main WebSite is www.copdcanada.ca

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Name:	Phone #
Full Mailing Address:	E Mail Address:
Are You a (Please Circle One) Patient, Caregiver, Family Member/Friend, Medical/Professional, <i>Other (if other please specify)</i>	How did you Hear about COPD Canada Patient Network? (Please circle) Internet Search, Family/Friend, Pamphlet, Newsletter, Referral Other <i>(If other or by referral, please specify)</i>
Do You have any Comments or Suggestions?	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. <i>(The above is applicable to Canadian members)</i>

Please Note: All information gathered/received will be held in the strictest of confidence and WILL NOT be shared with anyone at any time (with the exception of your name (only) in the event a supplier wants to verify your membership) Your personal information will NEVER be compromised. Once we receive your application, a welcoming note will be sent to you with additional information along with your Membership Number, the most recent Monthly "AIRmail" and Newsletter.

"Together" We CAN !!! Care, Advocate, Network