



# Alpha-1 Canada Community News

November 2011

What's New at  
[www.alpha1canada.ca](http://www.alpha1canada.ca)

- Learn more about, and take up the Alpha-1 Canada 10-10 Challenge
- New Support Groups to Launch across Canada

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## Guest Speaker on Nutrition at Alpha-1 Canada's Annual General Meeting

by Jim Mundy

The law requires that every year we hold an Annual General Meeting (AGM). Organizations' annual general meetings can be pretty boring and dry affairs filled with things like approving the previous year's audited financial statements and appointing an auditing firm to review next year's financial statements.

For the last couple of years we've tried to spice the AGM up by having a guest speaker. The dry and boring legal part only takes ten to fifteen minutes and then our guest speaker takes over, gives an interesting presentation and answers your questions.

This year's AGM will be by telephone conference call on Tuesday November 15th and our featured guest speaker will be Beth Haliburton, BSc, BASc, RD. Not only is Beth a registered dietician at Toronto's Hospital for Sick Children, she is also one of the newest members of our board of directors.



Beth will be speaking on General Healthy Eating and Nutrition in Alpha 1. Several of our readers have told us that this is an area that concerns them and we are certain that Beth will provide you with invaluable information.

Beth has a Bachelor of Science in Biology from Dalhousie University and a Bachelor of Applied Science in Nutrition from Ryerson University. She completed her practical internship at The Hospital for Sick Children (SickKids) in Toronto.

After completing her training, she worked at SickKids in the department of Gastroenterology, Hepatology and Nutrition, and is now working in the department of General Surgery.

The times for the conference call on November 15th are:

<b>BC:</b> 4:00 PM	<b>AB &amp; SK:</b> 5:00 pm	<b>MB:</b> 6:00 pm
<b>ON &amp; QC:</b> 7:00 pm	<b>NB, NS &amp; PEI:</b> 8:00 pm	<b>NF:</b> 8:30 pm

Please join us.

At the appointed time dial 1-800-508-7891. When prompted, the meeting number is \*905 614 559 1\*. The asterisks (\*), before and after the meeting number, are required.

"See" you then!

**Read more  
about**



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## The Alpha-1 Canada 10-10 Challenge

by Jim Mundy

We recently sent you an e-mail and updated our Facebook page and Twitter to invite you to take part in our 10-10 Challenge from October 17th to Nov 30th, 2011, help us raise awareness of Alpha-1 and much needed funds in a fun and easy way.

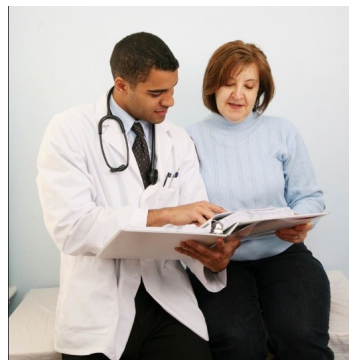
We are certain that every Alpha will want to do their part and take up the Alpha-1 Canada 10-10 Challenge. Indeed, many have already begun and one enterprising Alpha has already mailed us \$100.

### What is the 10-10 Challenge?

Simply put, we are asking YOU to ask 10 people to donate \$10 to help support Canadians suffering from Alpha-1.

Whether you are an Alpha yourself, a caregiver, parent, relative or friend of one - or one of our many supporters, please take up this challenge. People just like you are counting on your support. Donations in any amount are always needed and greatly appreciated.

These new funds will go toward innovative programs and services for which other funding is simply not available or difficult to come by.



There are a very small number of Canadian infants, children and teens affected by Alpha-1. But these young people are affected in very profound ways. They, their parents and brothers and sisters need support that is quite different from the help we are able to provide for adults. Some of the funds raised through the 10-10 Challenge will be used to develop and deliver programming for infants, children, teens and their families who are affected by Alpha-1.

Many adult Alphas have told us that they would really find it helpful to meet other Alphas in person.



Given the small number of Alphas in Canada and our vast geography this poses incredible challenges. While our new on-line support groups are allowing Alphas to meet Alphas in a virtual environment, the Board of Directors has made it a priority to hold in-person Patient Education Days in the future.

The first is scheduled for April 14th, 2012 in the Toronto area. The second, to be held in 2013 in Alberta will be followed by more in other provinces. Again, some of the funds raised through the 10-10 Challenge will be used to make these meetings a reality.

Finally, our 2008 mailing to all family doctors, respirologists and hepatologists in Canada was very successful



in raising awareness in the medical community but we need to do additional work in this area if the estimated 5,000 Canadian Alphas are to be diagnosed properly. Some of the funds raised through the 10-10 Challenge will be used to reach out to more doctors on a regular basis to inform them about this disease.

The Alpha-1 Canada 10-10 Challenge is just one way you can help ensure that these programs and services happen for Canadian Alphas, their parents, caregivers and families.

All of the information and pledge forms you will need to take part are available on a special page of our web site which you can access by clicking [here](#) or call Jim Mundy at 1-888-669-4583.

We all know ten people who we could ask for support. For example, family, friends, Facebook friends, Linked-In Contacts, neighbours, co-workers, business associates, committee members, team members (bowling, curling, golf, etc.), physicians, respirologists, rehab therapists, even home oxygen suppliers.

Thank you for your on-going support!

### Tip of the Month

Be good to yourself.

Ongoing positive reinforcement helps create an effective barrier to stress.

Sometimes the best defence is a good offence.

When it comes to stress that means taking steps to prevent it. Sounds impossible?

To find out more, click on this link:

[http://www.morethanmedication.ca/en/article/index/Prevent\\_stress](http://www.morethanmedication.ca/en/article/index/Prevent_stress)

**SAVE THE DATE:****ALPHA-1 CANADA  
PATIENT EDUCATION  
DAY**

Alpha-1 Canada is excited to announce that an Education Day will be held on April 14, 2012 in the Greater Toronto Area.

This will be the first of many across the country.

We are gathering guest speakers and information about lung, liver, and Alpha-1 in infants and children.

More details will follow as they become available.

Mark your calendar and be sure to join us.

We are always open to suggestions. Let us know if there is a particular guest speaker or topic you would like to hear.

**Support Group Participation****by Jim Mundy**

Alpha-1 Canada is proud to announce that our support groups are reporting positive feedback. Some of their comments are:

"Amazing to hear the commonalities of other alphas", "Nice to know that collectively we can discuss and respond to situations affecting our Health", & "Happy to be a part of reciprocal sharing with alphas".

That being said, you can still participate!



We would like to continue to hear from people who would like to lead or be members of support groups for Alphas as well as caregivers and parents of children affected by Alpha-1. Ultimately, we would like to set-up at least one group in each province. However, we can't make that happen without your participation.

Our support groups will be made up of people with common interests and experiences - people just like you. People who have been through, or are going

through, similar circumstances can do more than sympathize with each other; they can relate to what each are going through and keep each other from feeling like they are alone.

This is especially true in the case of rare diseases like Alpha-1 where the sum of all the information the members know is much greater than any one member could possibly know. The support group leader and members together can share information about, medical treatments, nutrition, informed healthcare providers, promising medical research, links to researchers, financial assistance, travelling with oxygen and drug and treatment reimbursement to name a few.

In fact, research indicates that attending support groups can be good for your health. Patients who participate in support groups - in addition to adhering to their medical treatments - report less anxiety and depression and actually live longer than those who do not attend. It is speculated that having the social support of others in the group boosts the immune system by reducing anxiety and psychological stress.

Our new on-line support groups will use the significant power of the internet



to bridge the miles and bring people affected by Alpha-1 together. Together, all the members can feel that the rest of the group is right there in their home with them. That being said, if you would like to be part of a telephone support group, do not hesitate to let us know.

Please take this opportunity to support yourself and others and be a part of making a difference in the lives of other Alphas.

Contact us today if you are interested in being a leader or a member of one of these on-line groups or if you have any questions ([jim.mundy@alpha1canada.ca](mailto:jim.mundy@alpha1canada.ca) or 1-888-669-4583)!

A special thank you is extended to the Ontario Trillium Foundation for making this training module possible. Additionally, the Board of Directors would like to publicly thank Jim Mundy, our Executive Director, for writing the training manual, facilitating the training of group leaders and for being a group leader of parents of children with Alpha-1.

**On-line Patient  
and  
Caregiver Support**



## One of our Alphas Makes National Headlines

by Vanessa McLaughlin

One of our very own Alphas, Eileen Anderson, made the CTV National News last month during a health segment on chronic obstructive pulmonary disease (COPD) by medical specialist Avis Favaro.



A new Canadian study, whose results were published in *The Lancet*, found that one out of every four people over the age of 35 can expect to develop COPD in their lifetime. In fact, researchers say the risks of developing the disease are much higher than the risks of breast cancer in women or prostate cancer in men; the average 35-year-old woman is more than three times as likely to get COPD than breast cancer during her lifetime while the average 35-year-old man is at more than three times greater risk of developing COPD than prostate cancer. Despite these results, the disease does not receive widespread recognition or awareness.

Eileen highlighted the cost of this chronic disease as she has been in hospital 11 times because of her condition: "The health care costs (of this disease) are phenomenal. You become a burden to friends and family, and that's hard," she told Avis Favaro while undergoing a rehab programme at West Park Health Centre. Eileen also brought to light that COPD is not always caused by smoking; hers was caused by Alpha-1 antitrypsin deficiency. Other

causes of the disease include regular exposure to second-hand smoke, air pollution, or exposure to chemical fumes or dust from the workplace.

When Avis Favaro asked Eileen to write about her genetically-induced Alpha-1 antitrypsin deficiency, she wrote the following:

*The roots of your COPD problems may be in your family tree.*

*Alpha-1 antitrypsin deficiency (alpha-1 for short) is an inherited disorder that can cause early onset, irreversible COPD, or chronic obstructive pulmonary disease. It is in your genes, so it is not something that goes away. That also means that you and your siblings might pass this onto your/their children or grandchildren.*

*Everyone's liver produces alpha-1 antitrypsin (AAT). The job of AAT is to protect the body from inflammation, especially in the lungs. In people with alpha-1 their AAT is malformed and can not be released by their liver. Most commonly this leads to lung disease but the build up of AAT in the liver can also lead to liver disease.*

*Over 20 years ago, after many complications with my health and many physician contacts, I found out I had Alpha-1. From the time I started experiencing symptoms of breathlessness in my 30s to the time I was diagnosed took 12 years. This came after 10 years of allergy shots, numerous misdiagnosed asthma flairs, overall chronic lung problems with extensive use of cotersteroid inhalers, antibiotics, emergency room visits and hospitalizations.*

*There is an easy way to find out if you have this inherited disorder and that is by having a simple blood test. For more information about testing, contact Alpha-1 Canada. The Alpha-1 Canadian Registry provides information on research and testing, and you can visit their [website](#) or call 1-800-352-8186.*

*If you are experiencing asthma that doesn't get better with medications, emphysema with or without a history of smoking, bronchiectasis, allergies that last all year and never seem to go away, a newborn, children or adults with unexplained liver disease ask your doctor about being tested.... Take the opportunity to educate yourself with the help of Alpha - 1 Canada to stay informed as to how you can best protect your health now and in the future.*

*Generating awareness from a personal perspective,*

*Eileen Anderson*

On behalf of Alpha-1 Canada, we would like to thank Eileen for promoting awareness about COPD and Alpha-1 antitrypsin deficiency. To see Eileen Anderson's interview with Avis Favaro, please click on the links below:

<http://healthblog.ctv.ca/post/Study-puts-urgent-focus-on-disease-that-will-hit-1-in-4-Canadians.aspx>

[http://www.ctv.ca/CTVNews/Health/20110908/copd-lifetime-rismites-110908/#.TmlncwW0\\_uY.email](http://www.ctv.ca/CTVNews/Health/20110908/copd-lifetime-rismites-110908/#.TmlncwW0_uY.email)

If you know of any Alphas making headlines, please contact us so we can share their stories.

### Donations

**Make Alpha-1 Canada your charity of choice.**

Moreover, take it a step further and ask your friends and relatives to do the same.

Your donations throughout the year are used to support a number of programs and services for Canadians suffering from Alpha-1 Antitrypsin Deficiency and their caregivers, such as the patient support hotline, the bilingual newsletter and website, and many more.

If you are able, please consider making a donation to Alpha-1 Canada today.

We gladly accept a cheque or money order made payable to "Alpha-1 Canada" or by credit card securely through [CanadaHelps.org](#).

If you are a regular supporter of your local United Way you can designate that all or part of your donation be directed to Alpha-1 Canada.

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## Household Hazards for Alphas

by **Vanessa McLaughlin**

Our attention was recently drawn to the article "Many homes harbor dust, fumes, germs, and other irritants that aggravate COPD symptoms" by David Freeman.

He reminds us our homes harbor dust, fumes, germs, and other irritants that aggravate COPD symptoms like wheezing, coughing, shortness of breath, and chest tightness. These risks are especially high for COPD sufferers who also have allergies. What might surprise you is that our homes contain less known household hazards.

Here are his top nine household hazards for people with COPD:



### 1. Air Ducts Filled With Dust

*Fact:* The forced-air heating and cooling systems found in many homes can blow dust and other irritants throughout the house.

*Action:* Don't forget to clean the air ducts periodically.

### 2. Carpets That Collect Dust and Dirt

*Fact:* Rugs and carpets are

a major source of dust and dirt. New carpets can be especially irritating, because they can "out-gas" formaldehyde and other noxious organic compounds for an extended period of time after installation.

*Action:* Consider bare wood floors. To further minimize the threat posed by dust, leave shoes at the door and arrange to have someone who doesn't have COPD dust, sweep, vacuum, etc.

### 3. Cleaning Products That Give Off Fumes

*Fact:* Oven cleaners, spray polish, and other household cleansers -- especially those that contain bleach or ammonia -- can be very irritating. "

cleaning products should be tightly capped and put away.

If someone with COPD must use cleaning products, the COPD Foundation recommends wearing a respirator mask rated "N95" by the National Institute for Occupational Safety and Health.

### 4. Dry Cleaning Chemicals

*Fact:* Some people with COPD are sensitive to the odor of newly dry-cleaned garments.

*Action:* Take the clothes out of the plastic and let them air out before putting them in your closet.

Alternatively, put them in a room with an open window -- and close the door. You might also look for a "green" dry cleaner that doesn't use harsh chemicals.

### 5. Fireplaces and Wood Stoves

*Fact:* A roaring wood fire gives off light and warmth -- and all manner of irritating gases and sooty particulate matter.

*Action:* Consider using a fake fireplace.

### 6. Moisture That Breeds Bacteria and Mold

*Fact:* From shower stalls to basements to that sponge left lying by the kitchen sink, sources of moisture in the home can promote the growth of bacteria and mold.

*Action:* Seal all leaks. Wipe up spills right away, and throw out water-damaged carpeting. Use fans to increase ventilation in bathrooms and kitchens.

*continued on page 6*

*Action:* Replace fume-producing products with less-irritating "green" cleansers or relying on old-fashioned cleaning agents like soap and water, baking soda, and vinegar.

The room being cleaned should be well ventilated, and someone who doesn't have COPD should wield the mop and scrub brush (and the person with COPD should steer clear until the job is done). After use,

## Household Hazards for Alphas

*continued from page 5*

Replace kitchen and bath sponges frequently.

Pick up a humidity meter and take steps to keep indoor humidity below 40% -- for example, by running a dehumidifier or air conditioner.

### 7. Pet Dander and Dirt

*Fact:* Cats and dogs fill a home with love -- but also with irritating dirt and dander (bits of dry skin and hair).



*Action:* Have your pet washed and groomed twice a month. And keep them out of your bedroom.

### 8. Showerheads That Harbor Mycobacteria

*Fact:* Showerheads can harbor so-called "atypical mycobacteria." These germs are generally harmless to healthy people, but capable of causing a chronic, low-grade infection that brings coughing and shortness of breath in people with COPD. Mycobacteria are also resistant to antibiotics, making them hard to eradicate.

*Action:* Clean (or replace) showerheads twice a year.

### 9. Toiletries: Scented Soaps, Shampoos, Sprays

*Fact:* Some people with COPD are sensitive to scented

soaps, shampoos, deodorants, hairsprays, and cosmetics.

*Action:* Stick with unscented personal products - and steer clear of perfume and cologne.



If you know of any other household hazard to make it a top 10, please contact us with your information.

If you know of any research, articles or other publications that would be of interest to our readers please contact us.

## How do COPD patients respond to exacerbations?

by **Vanessa McLaughlin**

Although timely treatment of COPD exacerbations seems clinically important, nearly half of these exacerbations remain unreported and subsequently untreated.

Recent studies have investigated incidence and impact of failure to seek medical treatment during exacerbations.

Yet, little is known about type and timing of other self-management actions in periods of symptom deterioration.

That is why researchers, including Dr. Jean Bourbeau (pictured), who is a member of Alpha-1 Canada's



Medical Advisory Board, undertook a study which aimed at determining the relative incidence, timing and determinants of three types of patient responses.

In a multi-centre observational study, 121 patients were followed for 6 weeks by daily diary symptom recording.

Three types of action were assessed daily: planning periods of rest, breathing techniques and/or sputum clearing (type-A), increased bronchodilator use (type-B) and contacting a healthcare provider (type-C).

What they found was that Type-A action (sputum cleaning) was taken in 70.7%, type-B in 62.7% and type C in 17.3% of exacerbations.

Interestingly, smokers were less likely to take type-A and B actions.

Type-C actions were associated with more severe airflow limitation and increased number of hospital admissions in the last year.

As such, their study shows that most patients are willing to take timely self-management actions during exacerbations.

However, future research is needed to determine whether the low incidence of contacting a healthcare provider is due to a lack of self-management or healthcare accessibility.

The study was published in the August issue of BMC Pulmonary Medicine (Vol. 11:43).

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Visit us on the web  
at [alpha1canada.ca](http://alpha1canada.ca)

Our website is continuously updated with useful information for Alphas, their caregivers and healthcare providers, as well as news on promising research. Make a habit of checking our website regularly so you won't miss out on exciting updates and always read our monthly newsletter from top to bottom.

Help us spread awareness by sharing this newsletter with your family and friends.

If you would like to receive this newsletter by e-mail, please contact us at 1-888-669-4583 or [vanessa.mclaughlin@alpha1canada.ca](mailto:vanessa.mclaughlin@alpha1canada.ca)

This newsletter is designed to support, not replace, the relationship that exists between you and your physician. It is not the intention of this newsletter to provide specific medical advice but rather to provide the Canadian Alpha-1 Community with information to better understand their health and their diagnosed disorder.

Specific medical advice will not be provided and Alpha-1 Canada urges you to consult with a qualified physician for diagnosis and for answers to your personal questions.

**Alpha-1 Canada**  
**Making a difference in the lives of Alphas**

## Orphanet touches shore on the new world via a partnership with Québec

by **Vanessa McLaughlin**

Orphanet has forged a partnership with Québec to extend its rare disease and orphan drug information portal to the province as a pilot phase before extending to all Canadian provinces.

This means that information on Québec-based research entities, health care professionals, laboratories, and patient organizations will soon be available via the rare disease portal.

Orphanet, already available in 38 pan-European countries, is one of many rare disease stakeholders moving forward

international cooperation to improve information, care and treatment for rare disease patients worldwide.

The Québec-Orphanet project will be coordinated by the Department of Medical Genetics at the Montréal Children's Hospital - McGill University Health Centre.

With the financial support of the Commission Permanente de Coopération Franco-Québécoise, Québec will soon have its own Orphanet country site page listing local policy developments, conferences, and other news. It is estimated that rare diseases

affect 5% of Québec's population.

Orphanet is the reference portal for information on rare diseases and orphan drugs. It offers a range of freely accessible services, including an inventory of rare diseases and a classification of diseases elaborated using existing published expert classifications.

For more information, visit their website: <http://www.orpha.net/consor/cgi-bin/index.php>

orphanet