



Alpha-1 Canada Community News

December 2011

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www.alpha1canada.ca

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Season's Greetings



PASS THE LIGHT

For the ones we love,
For the Alphas we know,
And the ones we don't.

CHERISH THE GIFT OF KNOWLEDGE

Please join Alpha-1 Canada in lighting our 2nd annual multipurpose E-candle.



What better time of year to spread awareness, education and support about our disease locally, nationally and internationally in combination with your Season's Greetings. All you have to do is forward the E-card that we sent on Friday, December 16th on behalf of Alpha-1 Canada to your family and friends and ask them to do the same. Or better yet, forward this newsletter.

We thank you in advance for your participation and we look forward to making this simple activity a resounding, annual, global success.

Wishing You All the Blessings of the Season,

Staff and the Board of Directors of Alpha-1Canada



Exercise your heart this holiday season: The Alpha-1 Canada 10-10 Challenge

by Jim Mundy

The Alpha-1 Canada 10-10 Challenge has been so successful that we've extended it to the end of December.

If you have not done so already, please join this initiative and help us raise awareness of Alpha-1 and much needed funds in a fun and easy way.

The two people who have raised the most funds so far are from the west, one in BC has raised an impressive \$3,390 and one in Saskatchewan has raised \$410.

In fact the person in Saskatchewan who has raised \$410 has asked her family to make donations to Alpha-1 Canada instead of giving her Christmas gifts this year.

Even some of our international friends who follow our website and newsletters have joined in our cause.

On behalf of the board of directors and the patients, parents and caregivers who will benefit from the new programming these funds will allow, thank you very much!

Here are the details again:

Alpha-1 Canada invites you to take part in our 10-10 Challenge from October 17th to December 31st, 2011.

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 Spring 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.

There will be two prizes awarded. The first will go to the person who raises the most funds in the 10-10 Challenge. The second will be awarded by raffle from among all of the people who submit completed pledge forms.

Take up the 10-10 Challenge and do your part to make a difference in the lives of Alphas. You may even win a prize!

NEW: Ask the Professionals

We have a number of professionals in leadership positions at Alpha-1 Canada. There is, of course, our Medical Advisory Board (MAB) made up of Dr. Ken Chapman, Dr. Jean Bourbeau, Dr. Simon Ling and Dr. Diane Cox; all leading researchers and clinicians specializing in Alpha-1.

Our Board of Directors are also experts in their fields, whether that be business, healthcare, care giving or being informed patients. Connie O'Connor is a nurse at SickKids in Toronto and Beth Haliburton is a registered dietician at SickKids as well.

If you would like to ask one of them a question please e-mail jim.mundy@alpha1canada.ca and he'll pass on your question and get you the answer and then post it [here](#).

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Continued: Ask the Professionals

Please note that we do not have access to your medical history or test results so only general information questions can be answered here. For questions about your personal health please consult your physician.

View questions readers have submitted and read the answers from the professionals by clicking the link below:
http://www.alpha1canada.ca/ask_the_professionals

Drug Shortages

Below you will find an e-mail we received from Health Canada addressing drug shortages in Canada.

We are proud to say that our Executive Director Jim Mundy, on your behalf, has been and will continue to partake in all healthcare consultative processes where our government extends invitations.

Dear stakeholder,

As you may know, encouraging industry to work to close the information gap on drug shortages for Canadians has been a priority of Health Canada. As such, Minister Aglukkaq asked industry to establish a plan to address drug shortages.

The Minister recently received a plan developed by industry and health care professional associations which was very encouraging. Industry's commitment to post drug shortage information on existing public websites is an im-

portant first step to increase transparency on an issue that can have a significant impact on so many Canadians and those who care for them: http://www.druginfo.usask.ca/healthcare_professional/drug_shortages.php

Canadians will also be able to view drug shortage information at: <http://www.canadapharma.org/shortage/index.asp?l=en>

The Department is very pleased that such a diverse group of stakeholders is acting quickly and is committed to developing solutions on drug shortages to ensure that health practitioners have the tools they need to deliver high quality and patient-focused care to Canadians.

When the first phase of the plan is fully implemented and the creation of the establishment of a national one-stop drug shortages monitoring and reporting system in 2012 is finalized,

Health Canada will continue to encourage industry and health care professional associations to collaborate across the health system to develop best practice guidelines for the prevention and management of drug shortages. The goal is to help prevent drug shortages by addressing their root causes.

You will also note that Health Canada has created a Frequently Asked Questions web page for Canadians. This document is posted on Health Canada's website at:

<http://www.hc-sc.gc.ca/dhp-mps/prodpharma/activit/announce-annonce/shortage-rupture-eng.php>



Paul Glover
Sous-ministre adjoint
Direction générale des produits de santé et des aliments

Alberta Alpha Makes Headlines: Update

by Vanessa McLaughlin & Jim Mundy

You may have seen or read news stories last month about an Alpha-1 patient in Alberta, Sandie Tomlinson, who is trying to get coverage from her provincial government for augmentation therapy (Prolastin-C).

We can now update you on the story to let you know that Grifols, the company that produces Prolastin, made a submission on December 15th, 2011 to the Alberta government to have it placed on their formulary.

Alpha-1 Canada also made a submission to the Alberta

government which outlines patient reported outcomes from being treated with Prolastin.

Our submission was similar to one we made to the Ontario government earlier in the fall. Both documents are entitled "Living Proof" as they chronicle the stories of Alphas receiving treatment and one of the patients, from BC, quoted claimed that both she and her sister are "living proof" that the treatment works.



We have been informed by several sources that patient groups, such as Alpha-1 Canada, can significant impact the decision making of drug review committees. It is your life stories and input that carry the weight.

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Alberta Alpha Makes Headlines: Update

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For those patients who contributed to the submission we are grateful. For those that have yet to do so we need your stories to continue the battle together, for a positive outcome across our nation.

We would like to keep this story alive in Alberta to put pressure on the government to provide funding. But in order to do so, we need some help.

If you live in Alberta and are receiving treatment (Prolastin) or if you live in Alberta and your doctor has

prescribed Prolastin but you have been unable to get coverage, please get in touch with Jim Mundy at 1-888-669-4583 or jim.mundy@alpha1canada.ca.

Alpha-1 Canada is a lay organization and registered charity. As such we cannot and do not endorse commercial products, however, if any commercial product is prescribed to anyone with Alpha-1 Antitrypsin Deficiency by a qualified medical practitioner we advocate for equitable and affordable access to it.

We will continue to keep you updated and thank Sandie Tomlinson for raising awareness about alpha-1 antitrypsin deficiency.

If you would like to learn more about her story please click on the links below.

http://calgary.ctv.ca/servlet/an/local/CTVNews/20111116/CGY_alpha_drug_111116/011116/?hub=CalgaryHome

<http://www.calgarysun.com/2011/11/16/ahs-wont-fund-lung-meds-for-ailing-grandma>

Listen to our latest podcast

We have uploaded a new podcast to our website.

Our speaker on nutrition is 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.

In the podcast, Beth speaks about General Healthy Eating and Nutrition in Alpha 1. Several of our readers have told us that this is an area that interests them and Beth's podcast provides invaluable information.

Please visit the website and have a listen. The information Beth provides in her talk and her responses to questions is food for thought!

You can listen to the podcast [here](#) or visit our website and select "Educational Podcasts" under "Resources for Patients and Caregivers."

Rare Disease Day Dinner Gala: February 29, 2012, Ottawa Marriott Hotel



HOW WILL YOU CELEBRATE THE RARE?

On February 29? A day so rare it happens only once every 4 years, you could:

WEAR the RARE

By stepping out in your rarest most outrageous party dress! *

DARE the RARE

By imbibing some rare drinks with exotic foods!

SHARE the RARE

By passing the evening with some very rare Canadians!

Or DO ALL OF THIS

Join the Canadian Organization for Rare Disorders (CORD) at their 2012 Celebrate the Rare Gala on Wed Feb.

29, 6:30 p.m.

WHERE: Ottawa Marriott Hotel, 100 Kent St, Ottawa, Ontario (not so rare)

FARE: All drinks and foods rare (and not so rare)

PREPARE: For an evening of rare entertainment, laughter, awards, and auction.

BE AWARE: An evening this rare won't happen again for another 4 years!

Proceeds will support CORD's 2012 objectives and their partnership with the CIHR Rare Disease Emerging Teams Research Fund.

For information on how you can be a sponsor for Celebrate the Rare

Gala or donate to the Silent Auction, please visit their website www.raredisorders.ca or contact CORD at: info@raredisorders.ca

Tickets Prices:

Individual: \$150,

Patients/Non-profit: \$90,

Table for 10: \$1,500

*Dress attire is business smart, cocktail, or evening.



Rare Disease Day



SAVE THE DATE:**ALPHA-1 CANADA
PATIENT EDUCA-
TION DAY**

Alpha-1 Canada is excited to announce that an Education Day will be held Spring 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.

Can age and sex explain the variation in COPD rates across large urban cities in Canada?

by Vanessa McLaughlin

Researchers, including Dr. Jean Bourbeau (pictured), who is a member of



Alpha-1 Canada's Medical Advisory Board, undertook a study which aimed at measuring the prevalence of chronic obstructive pulmonary disease (COPD) and determine the effect of age and sex on the variation in prevalence across major cities within Canada and the health care system.

They used the Burden of Obstructive Lung Disease (BOLD) methodology to estimate the prevalence of

COPD in adults aged >40 years in different Canadian cities. The study used interviewer-administered questionnaires on respiratory, smoking and occupational history, medication use and comorbidities. Post-bronchodilator spirometry was used to classify subjects. They determined the prevalence and severity of COPD with and without adjustments for age and sex distribution across different cities.

In a study population of 3,042, they found that 16.7% of study subjects met the criteria for Global Initiative for Chronic Obstructive Lung Disease (GOLD) severity Stage 1 or higher. The prevalence according to the criteria for

the lower limits of normal of the ratio forced expiratory volume in 1 second/forced vital capacity was 11.6% (95%CI 9.9-13.3). COPD prevalence varied by severity across sites ($P = 0.0025$). After age-sex adjustment, the variation disappeared ($P > 0.16$).

Therefore, age and sex differences account for most of the heterogeneity in COPD estimates across large cities within the same country. Adjustments for age and sex are essential in comparing COPD rates across the country.

The study was published in The International Journal of Tuberculosis and Lung Disease. 2011 Dec;15(12):1691-8.

Irish hereditary emphysema rates found to be among highest in the world

by Vanessa McLaughlin

Researchers in Ireland from the Royal College of Surgeons in Ireland (RCSI), Beaumont Hospital, and Trinity College Dublin have conducted a study which has found that Ireland has one of the highest incidences of alpha-1 antitrypsin patients in the world.

The study raises the possibility that hundreds of people suffering from chronic lung disease could have this genetic condition but have yet to be diagnosed.

It is hoped the findings of this study will lead to increased awareness of the disease and earlier diagnosis which can contribute to a better quality of life for people with the condition.

Thought to be a rare dis-



ease, this study has revealed that Alpha-1 is much more common than was expected in Ireland.

1 in 25 Irish individuals were found to be carriers for the gene responsible for the most severe form of Alpha-1, making the condition the most common fatal inherited lung condition in Ireland after cystic fibrosis.

In its most severe form,

Alpha-1 is estimated to affect more than 2,000 people in Ireland. The study found that a further 10,000 Irish individuals are also at increased risk from a less severe form of the condition and an even larger number of 170,000 individuals are carriers of the condition and may be at risk of developing lung

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Visit us on the web
at 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

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

Irish hereditary emphysema rates found to be among highest in the world

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disease, particularly if they smoke.

In addition to examining the DNA of 1,100 individuals, randomly sampled from the general population, this study drew on results from the first 3,000 individuals screened as part of the ongoing Irish National Targeted Detection Programme for Alpha-1.

This screening programme tested individuals suffering from lung and liver disease

and identified over 80 Alpha-1 individuals and over 400 carriers of Alpha-1.

The team at Beaumont Hospital is working with around 25 hospitals around the country in an effort to identify Alpha-1 as early as possible.

In conclusion, their findings demonstrate that Alpha-1 in Ireland is more prevalent than previously estimated with Z and S allele frequencies among the highest in the world.

Furthermore, their targeted detection programme enriched the population of those carrying the Z but not the S allele, suggesting the Z allele is more important in the pathogenesis of those conditions targeted by the detection programme.

The study was recently published in the journal *Respiratory Research*, 2011; 12 (1): 91