



Alpha-1 Canada Community News

January 2012

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It ain't over till we say it's over

by Jim Mundy

We are almost reluctant to remind you but the battle to have government reimbursement reinstated in Ontario continues into its fourth year. Additionally, thanks to an enterprising patient in Alberta who went to the media with her story, that battle has opened on a new front.

To bring you up-to-date, four years ago this coming spring the Ontario government stopped approving funding for new patients who were prescribed Prolastin (the only brand of augmentation therapy approved for use in Canada). They continue to renew funding for those previously approved but refuse to process new applications.

In addition to a number of scientific submissions from the Grifols (formerly Talecris Biotherapeutics) the manufacturer of Prolastin, Alpha-1 Canada also made a scientific submission in January 2011, which was written by Dr. Kenneth Chapman. On November 11th 2011, Remembrance Day, we made yet another submission



grounded in patient outcomes. This second submission by us was based on the personal stories of dozens of Canadians from coast to coast to coast that have been fortunate enough to receive Prolastin.

Without the direct participation of these members of our community this submission would not have been possible. The document takes its name from a quote from a patient in British Columbia who wrote that she, and her sister, were "Living Proof" that Prolastin therapy is effective in preserving lung function and extending life.

Living Proof has been in the hands of the Ontario government since November and is being reviewed by them, we expect a response shortly.

Even as the ink on Living Proof was still drying, the same issue flared up in Alberta. Living Proof was quickly rewritten for the Alberta situation and submitted to the Alberta government on December 15th, 2011.

You can read both of these versions of living proof on our website at:

[Living Proof - Ontario - November 2011](#)

[Living Proof - Alberta - December 2011](#)

Alpha-1 Canada will continue to advocate for equitable and affordable access for people affected by al-

pha-1 antitrypsin deficiency to all forms of treatment that may be prescribed or encouraged by their qualified medical practitioners in Ontario, Alberta and everywhere else in Canada.

We should point out that the governments of British Columbia, Manitoba and Québec do pay for this treatment.



Unfortunately, the way these process work in the provinces and territories a patient group like Alpha-1 Canada cannot begin the approval process. We will however, work to convince those who can begin those processes to do so and we will take an active role in ensuring those approvals.

Baseball great Yogi Berra, is famous for many sayings including, "It ain't over, 'til it's over." In the fight for equitable and affordable access to treatment you can rest assured that these battles ain't over till we say they're over!

The Alpha-1 Canada 10-10 Challenge

by **Jim Mundy & Vanessa McLaughlin**

Thank you to all who participated in the 10-10 Challenge! You raised just under \$10,000 in a fun and easy way. These new funds will go toward innovative programs and service for which other funding is simply not available or difficult to come by.

The couple that raised the most funds in the 10-10 Challenge and won an oxymeter was Terry and Theo Vriezen. They kindly declined the prize. The second prize was awarded by raffle from among all who participated and the lucky winner was Barbara Mohr of Saskatchewan. She also won an oxymeter.

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, chil-

dren, 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 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, respirolo-



gists 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.

Once again, 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! We hope you will once again take up the 10-10 Challenge in 2012.

Raising Awareness about COPD and Alpha-1

by **Vanessa McLaughlin**

In our November Newsletter, we featured a now famous Alpha making national headlines.

Eileen Anderson made the



CTV News during a health segment on chronic obstructive pulmonary disease (COPD) in which she highlighted the cost of this chronic disease as she had been in hospital eleven times because of her condition. Two of those stays were in the Respiratory Rehabilitation Service at West Park Healthcare Centre. She discusses her latest stay at West Park and how it

changed her life in the article "Breathless: One in four at lifetime risk of lung ailment" featured in the Winter 2011/2012 issue of Healthy Together.

The magazine was delivered recently to 41,000 homes around West Park, and is available throughout the hospital.

You can read the article in full by clicking [here](#).

Tip of the Month

Icy streets, overcast skies and sub-zero temperatures can send even the cheeriest of Canadians into a funk. But if a shift in mood starts to become debilitating, you may be suffering from a type of depression that follows a seasonal pattern. If that sounds like what you're going through, here's what to do about it.

Seasonal Affective Disorder (SAD) is very real and can have a profound affect on your professional and personal life.

To find out more about the signs of SAD and what you can do to say goodbye to it click on this link:

<http://www.morethanmedication.ca/en/article/index/sad>

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.

Join with the Canadian Rare Disease Community to Advance our Shared Goals

by Vanessa McLaughlin

We are very excited to announce that the Canadian Organization for Rare Disorders (CORD), of which Alpha-1 Canada is an active member, is planning a number of events this winter to coincide with World Rare Diseases Day, February 29th, 2012.

The first will be their 4th Annual Action Day on Parliament Hill in Ottawa on Tuesday, February 28th, 2012. This will be followed by a Rare Disease Gala on February 29th and a Rare Disease Day Conference the following two days entitled: "Innovations in Research, Therapies and Policy for Rare Disorders." The first day will focus on new therapies and policy and the second day will highlight research initiatives.



This past year, for the first time, the Canadian govern-

ment is drafting regulations for an orphan drug regulatory framework. These regulations are encouraging and a significant step in the right direction for the rare disease community. Even though each rare disease only affects a few people, there are more than 7,000 rare diseases that together affect 3.2 million Canadians. Yet Canada is the only developed country without a national orphan drug / rare disease strategy.

With no orphan drug program, less than half of the orphan therapies approved in other countries even come to Canada and Canadian patients with debilitating and life-threatening rare diseases remain among the last to access therapies.

It has been nearly 30 years since the USA passed the first Orphan Drug Act and more than a dozen years since the European Union passed their orphan drug legislation. Although Canadians with rare disorders are feeling optimistic about Canada's engagement, your patient voice is now more important than ever to ensure that the needs of people with rare diseases are met.

We need your help in raising awareness and building momentum for the support needed to advance the policies and programs which affect those with rare disor-

ders. One way to do so is by writing to the Prime Minister and Health Minister Aglukkaq as well as your local MP. Sample letters can be found on our website by clicking [here](#). If you are unsure of who your member of parliament is or where to write to, you can find him or her using your postal code at the following web site: <http://www2.parl.gc.ca/parlinfo/compilations/houseofcommons/memberbypost-alcodes.aspx?menu=hoc>.

Of course, if you would like to join other rare disease patients and advocates in Ottawa, I can tell you from experience that you WILL provide a strong common voice to advocate for health policy and a healthcare system that works for those with rare diseases. It also gives a voice to alpha-1 antitrypsin deficiency and can create an opportunity to meet other Canadians and even Alphas, from coast to coast, for support and information.

For more information regarding Action Day or the upcoming conference, please contact Angela at CORD (416) 969-7431.



Rare Disease Day

29 February 2012

Patients and Researchers, Partners for Life!

Ontario Alphas, Mark your Calendars

by Jim Mundy

Please make time to attend the Patient Education Day on Saturday April 14th in Mississauga, Ontario at the Hampton Inn, Toronto Airport Corporate Centre, 5515 Eglinton Avenue West, Toronto, ON M9C 5K5.

The day will feature speakers on lung and liver manifestations of Alpha-1 as well as pharmacology, nutrition and Alpha-1 in infants and children. The speakers will also entertain your questions.

We are still working out the details, but we hope to be able to "broadcast" the event live over the Internet with the ability for those watching from home to send questions or at the very

least record it and make it available after the fact on our website.

Many people have been asking for these in-person events so we expect excellent attendance.

More details will be announced as they are finalized but you can always contact us with your questions (1-888-669-4583 or jim.mundy@alpha1canada.ca).



New Board Member

by Vanessa McLaughlin

We are thrilled to announce that Terry Vriezen from British Columbia has joined the Board of Directors.

Terry is a caregiver to her lung affected husband, a support group leader and has attended the last two US national conferences. She has made it her mission to become well-informed about alpha-1 antitrypsin deficiency since her husband's diagnosis.

Please join us in welcoming Terry.

Additionally, our special thanks go out to all current and past board members for their individual dedication, commitment and time, and for putting in countless volunteer hours over a three year term and often beyond. The Board members are your team, not only working to grow the organization, but most importantly working for YOU – Making a difference in the lives of

Alphas.

If you think you might be interested in a position on the Alpha-1 Canada board of directors, contact Jim Mundy for more information (jim.mundy@alpha1canada.ca or 1-888-669-4583).

The board usually meets on the first Monday of each month by evening telephone conference call.

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); 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.

If you would like to ask one of them a question please e-mail

jim.mundy@alpha1canada.ca.

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



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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