



Alpha-1 Canada Community News



May 2010

Alpha-1 Canada – Update

It has been very busy here over the last few months. Well it always seems to be busy, but lately exceptionally so. As this newsletter goes to press we are only days away from hiring a second staff person. Interest in working for Alpha-1 has been deep and the field of candidates is very strong. In the June newsletter we will introduce the newest member of the team.

We also have a co-op student doing research for us. Anita Shallal, BScN, R.N. is a registered nurse and student at the University of Windsor. In addition to being a student and working as a nurse, Anita is preparing to write the entrance exams for medical school. The research she is working on is about nutrition, specifically as it pertains to Alpha-1 lung and liver disease. When Anita's research is complete we will publish her findings and create new web pages and print material based on her recommendations. Our sincere thanks go out to Anita for her hard work. Her latest draft is very informative and we

Alpha-1 Canada	
Per 125 mL (87 g)	
Amount	% Daily Value
Calories 0	
Fat 0.0 g	0 %
Saturated 0 g +Trans 0 g	0 %
Information	100 %
Education	100 %
Support	100 %
Telephone	100 %
Website	100 %
Help	100 %
Vitamin A 100%	Vitamin C 100%
Calcium 100%	Iron 100%

look forward to publishing this unique advice.

We recently received a significant grant from the Ontario Government for a project related to support groups. The results of this project will not only benefit the Canadian Alpha-1 Community but groups that support people with other rare diseases as well. We will be looking for volunteers in a little while to take part in this project and will keep you posted.

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The annual US Alpha-1 Conference is early in June and Canadian Alphas, adults and children, will be well represented with attendees from British Columbia, Alberta and Ontario. Our Treasurer, Jerry Cunningham and Executive Director, Jim Mundy will also be there. For those who cannot attend, the Alpha-1 Association will post recordings of the conference sessions on their website shortly after the conference. We will let you know when they are available..

Our Annual General Meeting (AGM) will be held by conference call on Thursday June 24, 2010. More details will follow in the near future.

Please keep your letters going to Helen Stevenson. The augmentation therapy funding situation is far from being resolved and we still need your help! Please ask all your friends and family to support you in this endeavour by mailing their letters today. A sample letter can be found here.

Please remember to pass the newsletter along to friends and family to help increase awareness, the newsletter on the website has been changed to make printing it much easier. If you use social media like Facebook, MySpace or Twitter, please use them all and watch our outreach grow.

Alpha Plans to Bicycle Across Saskatchewan

We were recently contacted by Samuel Carey, a liver-affected Alpha from Saskatchewan and his friend PJ. Samuel plans to ride his bicycle across Saskatchewan to raise awareness of Alpha-1 antitrypsin deficiency and Alpha-1 Canada.



Samuel told us that, "In recent months I found your website and it has shown me how to manage my genetic disorder, and now I have found a great deal of energy and a noticeable increase in health and vigour."

Samuel and PJ have started a blog which can be found at www.samuelcarey.blogspot.com. At the blog you can follow Samuel's gruelling training and particulars on how you can help. Travelling across a province the size of Saskatchewan can be an expensive proposition and any help you can provide would be greatly appreciated by Samuel and PJ.

P.J. called recently with great news, "I'm so excited! I just got our first official sponsor. I went into Staples to make some copies of my sponsorship proposal and I started to tell them about Samuel and his trip. The Store Manager gave me a \$25 gift card which I immediately used to make the copies."

Check out their blog and support this important awareness initiative.

Interesting Research

A Fatty Meal Can Increase Lung Inflammation

The prevalence of asthma has increased significantly over the past few decades. One factor implicated is the increase in obesity and the typically high-fat Western diet. Most people think that a high fat diet only affects health over a long period of time. However, Australian researchers have found that one high fat meal can increase inflammation and reduce lung function immediately, in people with asthma at least.

For the study, Lisa Wood PhD, a research fellow at the University of Newcastle in Australia, and colleagues recruited thirty non-obese people and 16 obese patients with asthma. The non-obese volunteers were randomly selected to receive either a high-fat meal or a low-fat meal. All of the obese participants received a high fat meal.

The 1000-calorie high-fat meal consisted of fast-food hamburgers and fries, contributing about 50% of calories from fat. For reference, the American Heart Association recommends no more than 25-35% of calories come from fat. The low-fat meal was 200 calories and 13% fat, consisting of a low-fat yogurt.

Sputum samples and lung function were tested at the start of the study and four hours after the meal.

The researchers found that markers of airway inflammation, called neutrophils, increased significantly while lung function was reduced among those who ate the high-fat meal. The volunteers who used an asthma inhaler containing albuterol after the high-fat meal had an impaired response to their medication.

It was known that dietary fat, particularly saturated fat, can activate an immune response in the TLR4 mRNA gene and cause an inflammatory reaction in other parts of the body, but this is the first study that has looked at the effects of a high-fat challenge on inflammation within the airways. Although the people in the study had asthma, inflammation of the airways is also a condition Alphas would do well to avoid.

Dr. Wood and her team plan further research but suggest that methods to reduce dietary fat intake may be useful in the management of asthma. "Further work is needed to understand the clinical relevance of these observations. Nonetheless, a difference of 3 to 4 percent [in lung function] is approaching a level which can be perceived by patients," said Dr. Wood.

She also said that they do not yet know how long these effects might last, but that if someone is consuming high-fat foods every day, they may be experiencing inflammation for at least several hours each of those days.

The research was presented in May 2010 at the American Thoracic Society's International Conference in New Orleans.



The following are summaries (abstracts) of recent studies of Alpha-1 and COPD including one by Dr. Jean Bourbeau who is a member of Alpha-1 Canada's Medical Advisory Board.

Because of copyright law we can only provide abstracts, if you want to read more check and see if your local library may have these journals on their shelves.

Preventing Hospitalization for COPD Exacerbations.

Bourbeau, Jean, Department of Medicine, Division of Pulmonary Medicine, McGill University, Montréal, Québec, Canada.

Published in Seminars in Respiratory and Critical Care Medicine, 2010 Jun; 31(3):313-320.

Abstract

Severe chronic obstructive pulmonary disease (COPD) exacerbations requiring hospitalization are a major cause of morbidity and mortality. Recognition of the importance of COPD exacerbations has led to the knowledge that prevention of exacerbations and early treatment are important goals of COPD therapy. Preventive management of COPD aiming at reducing exacerbations complicated by hospital admissions includes vaccination, avoiding pollutant exposure, and, when indicated, long-term oxygen therapy. Landmark studies have shown benefits of long-acting inhaled bronchodilators and combined long-acting inhaled bronchodilators with corticosteroids. The combination of a long-acting muscarinic antagonist with a long-acting beta (2) agonist and inhaled corticosteroids offers the best possibility to reduce the risk of exacerbations requiring hospital admissions. Pulmonary rehabilitation in COPD patients at risk of being hospitalized and regular physical activity have been shown to be associated with a lower risk of hospital admissions. Recent advances in the delivery of evidence-based care including a collaborative multi-component self-management intervention can reduce the risk of COPD hospital admissions. If physicians meet best practices, this will have potential clinical implications, including a reduction of hospitalizations. Novel pharmacological therapy, which can prevent disease progression and exacerbations, is still needed. New self-management strategies such as a written action plan that helps patients recognize their exacerbation and promptly access treatment may have great potential. This needs to be evaluated in a properly designed randomized clinical trial before it becomes the standard of care for COPD patients. © Thieme Medical Publishers.

Alpha-1 Antitrypsin Deficiency: Whom to Test, Whom to Treat?

Sandhaus R.A., Department of Medicine, National Jewish Health, Denver, Colorado.

Published in Seminars in Respiratory and Critical Care Medicine, 2010 Jun; 31(3):343-347.

Abstract

Alpha-1 antitrypsin deficiency (AATD) is the major identified genetic risk factor for chronic obstructive pulmonary disease (COPD). The biochemical events leading to lung destruction in AATD are well understood, and most of our understanding of the pathogenesis of COPD in general has been acquired through the study of AATD. There is a growing appreciation that early diagnosis of AATD can affect the course of disease and allow for appropriate treatment decisions to be made. Although there is published guidance regarding testing and treatment of AATD, the impact of this guidance has been minimal. AATD is underdiagnosed, and the evidence for current treatment recommendations is not without controversy. This article reviews the current recommendations for testing and treatment of AATD. Some of these recommendations are expected to change as legislation to prevent genetic discrimination is refined and new therapies for this relatively common

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genetic predisposition are developed. Additional genetic modifiers of COPD will be found, and the path set by AATD will facilitate their incorporation into our future management of COPD. © Thieme Medical Publishers.

Improving diagnosis and management of alpha-1 antitrypsin deficiency in primary care: translating knowledge into action

Fromer L., University of California at Los Angeles & Western University of Health Sciences, Los Angeles, California, USA.

Published in COPD. 2010 Jun; 7(3): 194-200.

Abstract

Alpha-1 antitrypsin (AAT) deficiency is an established genetic risk factor for pulmonary disease and may lead to severe emphysema. Despite accessible, inexpensive, and straightforward testing procedures, the disorder is still widely undiagnosed due mainly to a lack of awareness among the medical community. AAT deficiency often results in the development of non-specific respiratory symptoms that can be confused with those of other non-hereditary chronic obstructive pulmonary disease or asthma. However, there are published guidelines that provide detailed recommendations on patient testing. Early diagnosis of AAT deficiency is fundamental to improve patient outcomes; it allows preventive measures to be taken, such as smoking cessation, and allows monitoring and initiation of appropriate therapy while lung function is still relatively preserved. Diagnosis should not solely be the domain of the specialist pulmonologist; testing can be easily initiated in the primary care setting. The establishment of process maps and diagnosis algorithms, as suggested in this review, should encourage appropriate suspicion, testing, and follow-up of AAT deficiency in the patient's primary care medical home setting. Primary care physicians have a key role in increasing the awareness, diagnosis, and effective management of this disorder.

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 jim.mundy@alpha1canada.ca

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

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.

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