



Alpha-1 Canada Community News

April 2011

What's New at
www.alpha1canada.ca

- [Ontario withdraws funding for augmentation therapy. Join the fight to reinstate](#)
- [New Support Groups to Launch across Canada](#)

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Alpha-1 Canada is launching new support groups across Canada and we need you to participate

by Jim Mundy

Alpha-1 Canada is launching new support groups across Canada. We are looking for volunteer support group leaders and support group members in all provinces. There will be support groups for Alpha-1 patients, caregivers and for parents of Alpha-1-affected children.

Setting up and operating support groups in Canada for people with rare diseases like Alpha-1 has always been a challenge. In the case of more common diseases like cancer or diabetes for example, the pool of potential Members is large and creating a group in a town or even part of a town that can meet regularly and in person is a very real possibility.

The same cannot be said in the case of Alpha-1. Any given Alpha may be the only Alpha in town or the only Alpha for miles. This used to mean that support groups for people with rare diseases were not possible or required hours of driving.

We have found the solution to this quandary. Thanks to a generous grant from the Ontario Trillium Foundation, Alpha-1 Canada has developed an on-line model for support groups using Internet tools to bridge those miles and make support group attendance possible and easy for the majority of people with

Alpha-1, their families, caregivers and parents.

We have developed a support group leader manual and resource guide and training modules for volunteer support group leaders. All we need now is volunteer leaders to train and people to be support group members. If you are already a whiz with video chat this opportunity was made for you. And if you don't know anything about video chat here's your chance to learn and become a whiz.

For people without high speed internet, or even a computer for that matter, we are able to set-up support groups using only telephones and a toll free number. If enough people are interested we will certainly do that. Please let us know if this option will work better for you.



All support groups are made up of people with common interests and experiences. People who have been through, or are going through, similar circumstances can do more than sympathize with each oth-

er; they can relate to what each are going through and keep each other from feeling like they are alone.

However, many people are unaware of the additional benefits of joining a support group; support groups can be a great place to find practical tips and resources.

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.

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The problem, as we said, for people affected by a rare disease is that there are not others affected by the same disease close by to meet with. That is where the internet comes in to play.

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.

Using webcams, headphones, an internet connection and their computers, group members can 'get together,' see and hear each other and meet other Alphas in the comfort of their own home!

If you are interested in being a leader, a member of one of these on-line groups or if you have any questions please contact us right away (jim.mundy@alpha1canada.ca or 1-888-669-4583).

As mentioned above, if you do not have high speed internet, or even a computer for that matter, please let us know if you would be interested in a support group using only telephones and a toll free number.

We would like to set-up at least one group in each province although some provinces may need more and other smaller provinces like PEI may need to be combined together.



We would also like to hear from people who would like to lead or be members of support groups for caregivers and for parents of children affected by Alpha-1.

At the present time the manual and training materials are only available in English, however, we would welcome the opportunity to train leaders who are bilingual who could then lead French language support groups.

When asked about these new support groups, Mimi McPhedran, President and Chair of Alpha-1 Canada said, "Being involved as a group leader or a support-group member is not a daunting task nor will it be time consuming. Just 1 hour a month of your precious time is all it takes to be a support group member. The same applies for a group

leader, once the initial training is complete then a monthly meeting is mutually arranged and the benefits for all become endless. For most individuals, hearing another person's voice, seeing their face, interacting with presence and establishing friendships creates that personal connection that far exceeds any form of social media. Everyone at Alpha-1 Canada are so looking forward to finally 'seeing and meeting' each and every one of you. Please join us in linking all Alphas across Canada. Together, we will make a difference in the lives of alphas."

Once our on-line support groups are operating we intend to share our manual and training materials with other rare disease groups.

Please take this opportunity to support yourself and others and be a part of making a difference not only in your own life and the lives of other Alphas, but also in the lives of all rare disease sufferers. Please contact us today (jim.mundy@alpha1canada.ca or 1-888-669-4583)!

Tip of the Month

Experts say most mindless munching occurs during the weekend, so weigh-in on Fridays and Mondays to maintain your weight.

It's estimated that we make about 250 decisions about food every day, and some are mindless ones that could lead to overeating. But there is a healthier way. Listen to how you can go from mindless to mindful eating in a few steps.

To read more, please visit: http://morethanmedication.ca/en/article/index/mind_over_matter.

**On-line Patient
and
Caregiver Support**



Join us at the 20th Annual National Education Conference

The US Alpha-1 Association is holding a National Conference on June 10-12, 2011 in St. Paul, MN.

This conference is a great opportunity to network and learn from Alphas, their families and leading healthcare professionals. It provides an opportunity for all attendees to increase their understanding of Alpha-1, receive the latest information on research and treatments and to connect with other Alphas.

To learn more, please visit: www.alpha1.org/education/nateduconf.php

Benefits of On-line Support Groups

by Vanessa McLaughlin

A rare genetic disease is quite unlike most diseases as a diagnosis is not as easily made nor is access to treatment readily available – this can lead people who suffer from Alpha-1 antitrypsin deficiency to feel isolated; almost as if they are the only person who is going through what they are and that there is no help for them. In fact, they may be the only sufferer in town with that disease or the only person for miles. Therefore, creating a group in a town or even part of town that can meet regularly and in person is not a possibility.

But, support groups can be very helpful. Geographical distance makes no difference in on-line support groups. The Internet can bring Canadians with Alpha-1 together in a way that wasn't possible before. It can even lead some to finally speak, for the first time, with someone else with the same disease. In addition, research has shown that 80% of Internet users use the Internet for, among other things, finding health-related information. Since the most sought out information on the Internet is health-related, it makes sense that on-line Support Groups would be a workable solution.

The Center for Community Support and Research at Wichita State University (<http://www.ccsr.wichita.edu>) is internationally recognized as a leading resource for research on Support Groups, community coalitions, networks of community Members and non-profit health and human service organizations. A

thorough review of their research and the research they support demonstrates that patient led Support Groups have proven benefits as very effective tools in improving health outcomes.

This research demonstrates that Group Members experience:

- instant identity by interacting with others "who know how they feel"
- improvements in feelings of loneliness through a unique empathy from other Members which differs from that of professionals
- increased empowerment by encouraging them to take charge of their condition and a feeling of strength in numbers
- a feeling of safety in being able to ask questions in a safe, non-judgmental place about activities of daily living helping to redirect emotions and creating a level of accountability for their own health
- increased self-esteem and equality among Members, which has therapeutic benefits
- social role models develop and Members learn how others cope
- opportunities for mentoring



- a normalizing effect will occur where Members begin to view their experiences as "normal", understand that they are not alone and feel less isolated, depressed and stigmatized
- networking with others creates caring relationships, fosters roles other than "patient" and provides immediate access to help outside of meeting times
- information sharing provides practical approaches to life-style issues and the sharing of personal experiences to the benefit of others.

Our support groups can reassure you that there are others who understand what you are going through whether you are a patient, a caregiver or a parent of a child affected by Alpha-1.

You will learn about current medical research and become more informed about your condition and access to treatment in your province. Most importantly, you can expect to be given emotional support by the real experts ... Alphas.

What you will need when you join our Online Support Group

by Jim Mundy

Here's what you will need:

1. A high speed internet connection (not dial-up).
2. A computer with a Core 2 Duo 1.8 GHz (gigahertz) processor is ideal. A computer with a 1 GHz processor is fine.
3. A webcam and headset. The more money you spend on a webcam the more data you will be uploading to other members of your group and the slower everyone's connection will become. If you spend \$20 each on a webcam and headset the quality of your video and audio will be good enough. If you already have a webcam and headset, use them. The biggest reason for using a headset is so that you can hear other members well and they hear you better. If you have a built-in microphone and speakers on your computer and use them the whole meeting will sound to you like its taking place in a big empty room and that's how you will sound to everyone else.
4. A willingness to learn and actively participate in your group and a smile.



Fatigue and Pulmonary Rehabilitation

by Jim Mundy

A recent Canadian study suggests that COPD patients who experience higher levels of fatigue and shortness of breath during pulmonary rehabilitation exercise still experience many of the same benefits as their less fatigued counterparts and in some measures, even more benefits.

In the March 23, 2011 issue of the journal *Chronic Respiratory Disease*. Researchers at Mount Sinai Hospital Center in Montreal revealed their findings in a study entitled, "Fatigue in COPD: Prevalence and effect on outcomes in pulmonary rehabilitation."

The authors were M.A. Baltzan, A.S. Scott, N. Wolkove, S. Bailes, S. Bernard, F. Maltais and Dr. Jean Bourbeau who is a member of the Alpha-1 Canada Medical Advisory Board.

The study explains that, "patients with chronic obstructive pulmonary disease

(COPD) complain of dyspnea (shortness of breath) and fatigue. We sought to estimate the prevalence of high fatigue in this population and to determine whether individuals with high fatigue had a different response to pulmonary rehabilitation."

The researchers divided 251 individuals into low and high fatigue groups. They measured each patient's spirometry results, 6-minute walk distance, peak exercise capacity, constant workrate cycling endurance time, and two different questionnaires designed to measure health-related quality of life, including the St. George's and Chronic Respiratory questionnaires.

Patient's response to pulmonary rehabilitation was evaluated using changes in these measures at three months and one year after entry. High fatigue patients made up 39% of participants and they were younger, had more depressive

symptoms, greater shortness of breath and poorer health-related quality of life scores. They also had lower 6-minute walk distance, endurance times, and peak volume of oxygen consumption.

The researchers reported that, "Patients in both groups improved similarly in their shortness of breath, the 6-minute walk distance and endurance time."

High-fatigue patients had greater improvements in both fatigue and health-related quality of life scores, with clinically significant gains maintained at one year.

The researchers conclude that their study, "suggests that high levels of fatigue is a common feature in patients with COPD. They have a lower exercise capacity and a lower health status. However, they benefit from pulmonary rehabilitation."

Donations

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 considering making a donation, we gladly accept a cheque or money order made payable to "Alpha-1 Canada" or by credit card securely through CanadaHelps.org.

THANK YOU!

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

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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

Support Group Advantages

by Vanessa McLaughlin

A study by K. Wright and A. Muhstabad, "Perception of Support Group Advantages, Types of Support, and Support Providers," investigates on-line support group members' perceptions of supportive communication within on-line groups dealing with health-related concerns among on-line support

group participants.

The findings indicate that sense of community/similarity and lack of judgment/stigma were the most important advantages of on-line support group users, emotional and esteem support were perceived more positively than informational support, and participants had largely positive views of

on-line support providers.

Furthermore, the implications of the findings in terms of previous research on social support and computer-mediated communication are discussed.

You can read the full paper and findings at http://allacademic.com/meta/p12994_index.html.