Positive People in the Alpha Community

AlphaNet Unveils REACH Program

This year’s National Conference Celebrates the unveiling of AlphaNet’s newest program, REACH, or Risk Education to Achieve Continuous Health. REACH is a free, voluntary enrollment program specifically designed for individuals with Alpha-1 who currently do not require augmentation therapy. AlphaNet’s REACH program serves as a link to health maintenance information and activities tailored specifically to an individual’s health needs. Once a member of our REACH family, you will receive information about staying healthy with Alpha-1, as well as ongoing assessments to detect changes in your condition at the times you choose.

In addition, each individual enrolled in REACH will be assigned a personal REACH Coordinator to help focus on disease prevention and overall wellness. As a fellow Alpha, your Coordinator understands your circumstances and what it takes to live successfully with this condition.

Your REACH Coordinator will keep you connected to the Alpha community by contacting you at scheduled intervals and sending you relevant educational materials throughout the year. Your REACH Coordinator has special training and experience and will be a vital link to information about the management of Alpha-1.

Currently, REACH is focusing on the enrollment of Alphas with two abnormal genes (ZZ, ZZ/NAI, etc. — bar carriers will hopefully be eligible for inclusion in the program in the near future.

Enrolling in REACH can be accomplished in three easy steps:

1. Go online to www.alphanet.org/reach
2. Click on the Risk Assessment link
3. Complete the Alpha’s Risk Assessment Questionnaire

For more information about AlphaNet’s REACH program, please log on to: www.alphanet.org/reach, email: reach@alphanet.org or call: (855) 876-8422.

Story Ideas?
Do you have an interesting story that you think would make a great article for an upcoming issue of The AlphaNetter?
If so, please submit any ideas, comments and/or suggestions to Christine Lanser at clanser@alphanet.org.

SEPT 10-13: Alpha-1 Walk
Boston, MA
September 23-30 – 31: Midwest Workshops
Indianapolis, IN
September 30 – October 3: 23rd International Alpha-1 Conference
Kona, HI

CONGRATULATIONS! AlphaNet would like to acknowledge the following donors for their support in making this possible:
• Spencer/Robinson Driving Winser: October 2013: William Capen, Chester, DE. 
• Research: November 2013: Consumer 1, Blackwood, NJ.

Alpha-1 Foundation Event Calendar
August 10 – Alpha-1 Walk
Detroit, CO
September 26-28 – Escape to the Cape Bike-Trek
Cape Cod, MA
To find out more about these or other events in your area, log onto www.alphanet.org or call toll-free (888) 825-7421, ext. 253.

Inclusion means Cyndi with Alpha Kathy

Although National Nurse Week was celebrated from May 6-12, AlphaNet continues to pay tribute to the important role nurses play not only in society, but within our Alpha community.

To help raise awareness of nurses’ contributions and commitments everywhere, our very own Kathy Lee Collins, shares an uplifting, personal story about the relationship between inclusion and nurse, and just how the bond he kept a friendship going for over 20 years. Here is her story.

“On January 25, 1994, forty-three-year-old me, Kathy Lee Collins, was diagnosed with Alpha-1 Antitrypsin Deficiency. My pulmonologist told me ‘On January 25, 1994, forty-three-year-old me, Kathy Lee Collins, was diagnosed with Alpha-1 Antitrypsin Deficiency. My pulmonologist told me

She watched my husband’s cancer return and take him from me—from both of us, really, as I think she loved JD almost as much as I did.

At our recent celebratory dinner, we resolved that.

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AlphaNet launches AlphaNet Canada

AlphaNet, Inc. is proud to announce the launch of AlphaNet Canada, an organization dedicated to improving the lives of Canadians affected by Alpha-1 Antitrypsin Deficiency (Alpha-1). Sponsored by Grifols Canada, AlphaNet Canada provides support services to Alpha-1 patients, participates in clinical trials and collaborates with other organizations to provide education and disease management programs. Based in Erinbrook, Ontario, AlphaNet Canada is governed by a Board of Directors — a majority of whom are Canadian Alphas. Calendar events, clinical trials, and disease management programs are ongoing.

AlphaNet Canada is committed to “Alphas Serving Alphas.” As its motto demonstrates, AlphaNet’s mission is to make it easier for Canadian Alphas to get approved for augmentation therapy and hopefully make it easier for Canadian Alphas to get approved for treatment. “We want to help people learn how to stay as healthy as possible, grant their breathing conditions, by showing them around AlphaNet’s best health management resources, including The Big Reference Guide (BFRG),” AlphaNet Canada Program Manager and fellow Alpha, Mike Benn says.

Innomar Strategies is a program, community, and platform that serves as an ASMAR as the underpinning of the effort to improve the quality of lives of Canadian Alphas. This program has resulted in high augmentation therapy compliance with fewer exacerbations, unscheduled doctor visits and hospitalizations.

Working alongside Benn is AlphaNet Canada Coordinator David McKinney, who is a fellow Alpha and has been trained in the health management concepts that have proven successful for AlphaNet’s 5,000+ subscribers in the United States. Benn notes that all AlphaNet Canada Coordinators provide integrated services to different geographical areas of Canada. McKinney, who is fluent in French, oversees Alpha in Eastern and Central Canada. AlphaNet Canada is currently recruiting a Coordinator for Western Canada. Working in conjunction with the Provantis Direct to Patient Program, AlphaNet Canada has already secured close to 70 subscribers. According to McKinney, there are currently 120 individual Canadians who are using Provantis — the only approved augmentation therapy in the country. Benn explains that AlphaNet Canada’s goal right now is “to sign up as many of the 120 people partnering in the Provantis program alone, and start conversations as we can, and eventually increase this number to 5,000+ Canadian subscribers.”

“Significantly this is the first and only expansion of the AlphaNet brand. AlphaNet has partnered with Provantis to promote services that distribute Provantis and provides nursing support. Benn notes that AlphaNet Canada also plans to identify the following individuals: 1) Those currently on Provantis but not enrolled in the Provantis Direct to Patient Program via insurance coverage, 2) Those with associated pulmonary or liver disease who may be interested in augmentation therapy but have not been able to obtain it due to the health insurance issue, and 3) Those diagnosed with Alpha-1 who do not have a Provantis prescription and/or a Medicare card.”

Once AlphaNet Canada is up-and-running at full capacity, Benn says he would like to focus on some long-term objectives.

“Through the collection of data from subscribers involved in future clinical studies, we hope to show the value of infusion therapy and hopefully make it easier for Canadian Alphas to get approved for treatment.”

Spring Cleaning Your Allergies Away

Spring may be here, but for allergy sufferers, the start of sneezing, wheezing and other seasonal symptom misery may feel like winter just didn’t take the hint. Many of you with allergy issues are familiar with the start of sneezing, wheezing and other seasonal symptom misery. Aside from finding a way to punish Mother Nature, you can find some solace through a spring cleaning routine, which experts warn can help keep allergies at bay. Here are some useful tips to help you remove allergens from your home and prevent more from getting in.

Keep it tidy

One way to reduce your spring cleaning workload is to keep on top of things throughout the year. Change your air filters frequently, wash your window blinds with a H2O filter or a cyclonic vacuum, which traps allergens, and use a vacuum every two to three weeks.

Clean up as you go

Pet dander may be detected in certain parts of your home after a long winter spent indoors. If you keep a pet at home, vacuum your pet’s sleeping quarters weekly, wash your pet and pet bedding frequently, and speak to your veterinarian about a well-balanced diet for your animal, because a healthy pet may lead less dander.

Wash bedding weekly

Dust mites are the most common trigger of indoor allergy and asthma symptoms, so it’s wise to maintain exposure resistance to them in your mattress. To help decrease mite exposure, wash your bedding weekly, use water and dry on a hot cycle. If your comforters can’t be laundered, cover them with a washable duvet cover to keep them out of allergens. Use all-natural, unscented, hypoallergenic detergents and softeners. Avoid upholstery and pillows in allergen-proof covers.

Clean drapes and upholstery

It’s easy to forget to clean drapes and upholstery, as well as wall-to-wall carpeting and upholstery for pet hair, which are easier to clean and don’t harbor allergens. By: Teresa Kitchen, BSN, RN, AlphaNet Clinical Nurse Manager

AlphaNet Partners with Baxter Healthcare

AlphaNet has partnered with Baxter Healthcare to serve Alphas who are currently on Aralast ProCast or Aralast ProRho, as well as Alphas who are currently on Aralast ProNase. Baxter General Manager and will oversee the AlphaNet Baxter Coordinators Early Education and BaxterNet with over 20 years of management experience in customer service for healthcare organizations. “I am thrilled to start my journey here at AlphaNet and look forward to helping Alphas in the Arizona and Global community,” Collett said.

AlphaNet is excited for what lies ahead and we are certain that our collaboration with Baxter Healthcare will only serve to strengthen our motto “Alphas Serving Alphas.”

Clinical Corner

By: Teresa Kitchen, BSN, RN, AlphaNet Clinical Nurse Manager

• Insurance: Notify your AlphaNet Coordinator, doctor, home health agency, pharmacy and/or oxygen providers of any insurance changes that will occur soon or that have just recently occurred as early as possible to prevent interruption in your augmentation therapy and/or oxygen needs.

• IV Supplies: A tip for Provantis patients is to store Provantis supplies in a clear plastic bag for each infusion. This saves time and makes it easier for you or your nurse to provide an accurate supply to your AlphaNet Coordinator.

• Add-on/Vacation: Notify your AlphaNet Coordinator of any impending address changes or vacation plans. Having this information, again, prevents interruption in your care with augmentation therapy.

• Support Groups/Education Days: Ask your Coordinator about the support group in your area and where the next Alpha-1 Education Day will be held. These are great opportunities to meet other Alphas.

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Reminders from the Clinical Corner

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