

Positive People in the Alpha Community



Infusion nurse Cyndi with Alpha Kathy

Although National Nurses 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 Alpha, Kathy Lee Collins, shares an uplifting, personal story about the relationship between infusion nurse and patient, as well as the bond that has 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 about augmentation therapy and I was "all-in," as they say in poker. The arrangements were made with a local infusion center to send a nurse to my home for the weekly treatments. Although I didn't realize it then, my request to have the once-a-week infusion after work was unusual; only one nurse was willing to come to my home "after hours" at 5:30 p.m. every Thursday. Her name was then Cyndi Rohret.

Cyndi was five years my junior, and even though I've always been active, just watching her wore me out! I mentally took to calling her "Pollyanna" because of her sunny, incredibly positive attitude.

She occasionally reminds me that she was scared to death the first day we met, on February 2, 1994. Why? Because I am a lawyer. Apparently she was worried about what I might do if she screwed up my infusion. Cyndi is so good at her job that I haven't needed a port. The veins in my hands are holding up

like troopers!

This once-stranger at my home would sit with me and we'd talk every Thursday for about forty-five minutes. In the first year alone, we spent about 2,340 minutes, or 39 hours, talking and getting to know each other. On February 2, 2014, we celebrated twenty years of Thursdays and a wonderful friendship.

We've been through many personal highs and lows together, sharing life's good times with the bad. We've both changed jobs. Cyndi got a divorce. We've both lost beloved dogs, and we've both lost our precious mothers. We both fell in love and got married again. I've watched her son grow up, graduate high school, finish college, get married and become a father. 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.

During these twenty years, Nurse Cyndi, who had only an Associate's degree in Nursing when we met, went back to school to earn her B.S.N., then surprised us all by continuing her coursework and obtaining a double Master's in Nursing and Nursing Education. As an English teacher in my "previous life," I raised my hand to proofread and edit her papers. Cyndi credits me not only with being her cheerleader, but also with being her inspiration because I had put myself through law school after getting laid off from teaching.

Cyndi has twice saved my life by recognizing (when I didn't) that I needed to be hospitalized. When she had her hip replaced, and later when she broke her leg, I, the patient, drove to her house to receive my augmentation therapy. When I was given the option to switch to Medicare or keep my self-paid health insurance, I stuck with the latter because if I switched to Medicare, I would lose Cyndi, and I couldn't bear that.

At our recent celebratory dinner, we resolved to continue our professional and personal relationship for at least ten more years. I am hoping to break the record for longest-lived Alpha patient. Thanks to the expert care and love from my nurse, I wouldn't be against it!"

Community Calendars

Alpha-1 Association Education Days

co-sponsored by the Alpha-1 Foundation

June 6-8 National Conference
Kansas City, KS

August 23
Boston, MA

To find out more about conferences and support groups, visit the Alpha-1 Association website at www.alpha1.org or call toll-free: (800) 521-3025.

Alpha-1 Foundation Event Calendar

August 10 – Alpha-1 Walk
Denver, 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.alphaone.org or call toll-free: (888) 825-7421, ext. 233.

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CONGRATULATIONS!

AlphaNet would like to acknowledge the following SFS Monthly Sweepstakes Drawing Winners:

October 2013:
William Chapman
Gettysburg, PA

November 2013:
Constance Lilly
Woodstock, MD

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.

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The AlphaNetter

AlphaNet Unveils REACH Program

This year's National Education Conference marks the unveiling of AlphaNet's newest program, REACH, or Risk Evaluation to Achieve Continued 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 status. 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 if/when they occur. 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-1 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, SZ, ZNull, etc. — but carriers will hopefully be eligible for inclusion in the program in the near future.

Always Within REACH

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-1 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.

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, Ltd., AlphaNet Canada provides support services to Alpha-1 patients, participates in clinical trials involving Alpha-1 therapies and offers comprehensive health management and disease prevention programs.

Based in Etobicoke, Ontario, AlphaNet Canada is governed by a Board of Directors — a majority of whom are Alphas and Canadian citizens. AlphaNet Canada is committed to “Alphas Serving Alphas” and plans to contribute a portion of its excess revenues to Alpha-1 Canada to support awareness and advocacy.

“We want to help people learn how to stay as healthy as possible, given their breathing condition, by steering them toward AlphaNet’s best health management resources, including The Big Fat Reference Guide (BFRG),” AlphaNet Canada Program Manager and fellow Alpha, Mike Benn says.

AlphaNet’s Disease Management and Prevention program, commonly known as ADMAP, serves 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 3,500+ subscribers in the United States.

Benn notes that all AlphaNet Canada Coordinators will provide integrated services to different geographical areas of Canada. McKinney, who is fluent in French, oversees Alphas in Eastern and Central Canada. AlphaNet Canada is currently recruiting a Coordinator for Western Canada.

Working in conjunction with the Prolastin Direct Canada Program, AlphaNet Canada has already secured close to 70 subscribers.

According to Benn, there are currently 120 individuals in Canada who are using Prolastin — the only approved Alpha-1 augmentation therapy in the country.

Benn explains that AlphaNet Canada’s goal right now “is to sign up as many of the 120 people participating in the Prolastin Direct Canada Program as we can, and eventually increase this number to 250 Canadian subscribers.”

To accomplish this goal and expand its reach, AlphaNet Canada has partnered with Innomar Strategies, a pharmacy that distributes Prolastin and provides nursing services. Benn notes that AlphaNet Canada also plans to identify the following individuals: 1) Those currently on Prolastin but not enrolled in the Prolastin Direct Canada Program via Innomar Strategies; 2) Those that have prescriptions for Prolastin augmentation therapy but have not been able to obtain it due to health insurance issues; and 3) those diagnosed with Alpha-1 who do not have a prescription for Prolastin.

Once AlphaNet Canada is up-and-running at full capacity, Benn says he would like to focus on more 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 Clean Your Allergies Away

The arrival of spring means waving goodbye to the winter blues, but for allergy sufferers, it also means the start of sneezing, wheezing and other seasonal symptoms. Aside from reaching for meds, Alphas can find some relief through a spring cleaning routine, which experts note can help keep allergies at bay. Here are some useful tips on how to 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 every three months and use filters with a MERV rating of 11 or 12. Though taking your vacuum to the rug seems like an efficient way to zap allergens, irritants like dust mites and pet dander can easily be released back into the room while you clean. To prevent this, use a vacuum with a HEPA filter or a cyclonic vacuum, which traps allergens, at least once a week.

Clean up after your pets

Pet dander may be elevated in certain parts of your home after a long winter spent indoors. If you have pet allergies, vacuum your pet’s sleeping quarters well, wash your pet and pet’s bedding frequently, and speak to your vet about a well-balanced diet for your animal, because a healthy pet may shed less dander.

Wash bedding weekly

Dust mites are the most common trigger of indoor allergy and asthma symptoms, and they thrive on soft surfaces — which means your greatest exposure to them is through your mattress. To help decrease susceptibility, wash bedding weekly in hot (130°F) 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’ reach. Encase mattresses, box springs and pillows in allergen-proof covers.

Clean drapes and upholstery

It’s essential to wash, dry-clean or vacuum drapes, as well as vacuum sofas and chairs to remove lingering allergens, and wash or dry-clean throw rugs. When renovating rooms in the future, skip wall-to-wall carpeting and opt for hard floors such as hardwood, tile or sheet vinyl, which are easier to clean and don’t harbor allergens.

Don’t forget to dust

Because dust can aggravate symptoms in some people, it’s important to remember to clean out-of-the-way areas. Use a damp microfiber cloth to trap dust as you wipe down flat surfaces that rarely get cleaned, such as baseboards, door jambs, air duct vents, ceiling fan blades and Venetian blinds. After dusting, leave the room for 20 minutes to let the dust settle. And whenever possible, ditch clutter; it’s much easier to clean if you don’t have to dust around piles of paperwork and an assortment of knick-knacks.

Watch out for humidity

Moisture control helps reduce mold. Use bathroom fans and clean up any standing water immediately. Use detergent and water to scrub visible mold from surfaces and completely dry them. Use dehumidifiers in damp areas such as basements, and empty and clean the holding tank regularly. Run the air conditioning in humid weather to remove moisture from the air. Repair leaking roofs or drippy pipes, as chronic leaks allow mold to spread.

Keep the outdoors out

You may be tempted to open your windows to allow fresh spring scents into your home, but doing so can allow pollen particles inside. If you’ve spent time outdoors, launder your clothes and shampoo your hair to avoid carrying around allergens or transferring them to indoor surfaces such as sofas and bedding. You should also know that chemicals in air fresheners and candles can trigger asthma attacks.

Avoid harsh chemicals

Whenever possible, use cleaning products that are unscented or contain only natural ingredients. Or make your own all-purpose cleaning solution by combining one half cup distilled vinegar and two teaspoons of borax powder in half a gallon of water. Use this eco-friendly solution to wipe down surfaces and then let air-dry.

With these spring cleaning tips in mind, you’re well on your way to not only making your home look nice, but keeping your seasonal allergies under control.

AlphaNet Partners with Baxter Healthcare

AlphaNet has partnered with Baxter Healthcare to serve Alphas who are currently on Aralast and Glassia augmentation therapy products. AlphaNet Baxter Coordinators will function as an extension of Baxter Healthcare’s AATmosphere iNSPIRATION program, which is designed to support, empower and educate Alphas on Aralast and Glassia.

With the addition of Baxter, AlphaNet can now help all Alphas, as it serves patients using all four augmentation therapy products available in the US. This is truly a significant milestone and is the culmination of the vision of the founders of AlphaNet – Sandy Lindsey, Susan Stanley and John Walsh.

With the launch of the AATmosphere iNSPIRATION program, AlphaNet recently hired Kathleen Collett, who will serve as the AlphaNet Baxter General Manager and will oversee the AlphaNet Baxter Coordinators. Kathy comes to AlphaNet with over 30 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 Aralast and Glassia 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 of “Alphas Serving Alphas.”



AlphaNet Baxter
Program Manager -
Kathy Collett

Clinical Corner

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

Reminders from the Clinical Corner

- **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 Prolastin infusers; Place the needed infusion 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 count to your AlphaNet Coordinator.
- **Address/Vacations:** 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!

As always, the AlphaNet medical team is here to be a resource for you and your nurse. For questions about Alpha-1, feel free to contact me at tkitchen@alphanet.org or by phone at (888) 553-0093. Have a great summer!