

Winter 2011

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Study Indicates Alphas Living Longer

By: Robert A. Sandhaus, MD, PhD, AlphaNet Medical Director

Alphas usually live to be about 54 years old. At least, that's the number that has been commonly quoted for nearly two decades.

In 1994, the Danish researcher Niels Seersholm and colleagues reported in the medical journal *Thorax* on a study of 397 Alphas listed in the Danish Alpha-1 registry. They found the overall median survival of Alphas was 54.5 years – and this number has been widely cited ever since. (Median survival means that half of those in the study had died by that age, the other half lived longer.)

So, if you've been told that people with Alpha-1 only live to be about 54, the Danish study is likely the reason why. But a new and much larger study of Alphas conducted by AlphaNet between 1999 and 2010 tells a much happier story. The study included 2,365 people, all of them with severe Alpha-1 and nearly all on augmentation therapy for lung disease.

The median survival age in the AlphaNet study was 60.3 years. The news was even better for non-smokers, who lived a median of 65.5 years.

Robert A. Sandhaus, MD, PhD, Medical Director of AlphaNet, reported these findings in a poster presented at the American Thoracic Society (ATS) international conference in May.

Besides augmentation therapy,

everyone in the study was a part of AlphaNet's disease management program. Furthermore, there was no difference in survival between men and women.

"There are many potential explanations for the longer survival in our study compared to the 1994 Danish study," Sandhaus says. "There might be differences between the study populations, for example."

He suggests some other possible explanations: extensive use of augmentation therapy in the U.S.; "the well-documented effectiveness of AlphaNet's disease management program, which has been shown to improve quality of life, exacerbation frequency, and healthcare utilization"; and better overall understanding of Alpha-1 among treating physicians.

Sandhaus concludes, "Regardless of the explanation, this is good news for those treating Alpha-1, and especially for those diagnosed with Alpha-1."

As is the case with most studies, Sandhaus says the AlphaNet findings bring up valid questions for future study: Can further improvements be made? What is the effect of augmentation therapy on survival, since subjects included in the study were receiving augmentation? Can a patient-directed self-management program such as AlphaNet's actually affect survival?

Warm Up With this Winter Soup Recipe:

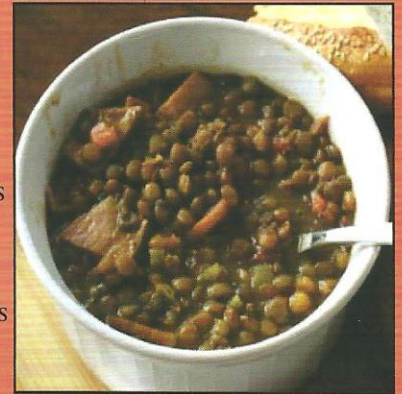
Hearty Lentil Soup

Yields 6 servings (about 11 cups)

Total Cook Time: 1 ½ hours

Ingredients:

4 lean cut bacon slices, diced	1 16-ounce package dry lentils
2 medium onions, chopped	1 teaspoon salt
2 medium carrots, diced	1 teaspoon pepper
2 cloves garlic, minced	½ teaspoon dried thyme leaves
2 stalks celery, chopped	2 bay leaves
1 ham bone (already cooked with some meat still remaining)	8 cups hot water
	2 tablespoons lemon juice



Directions:

In a large soup pot over medium-high heat, fry bacon until lightly browned; push to side of pan. Add onions, garlic, carrots and celery and cook over medium heat, stirring occasionally, until onions are tender, about 5 minutes. Add ham bone, dry lentils, salt, pepper, thyme, bay leaves and 8 cups of hot water. Cover; simmer over low heat for about 1 hour or until lentils are tender. Discard bay leaves.

Remove ham bone, add lemon juice and a pinch of salt into soup and stir thoroughly.

CLINICAL CORNER

BY: TERESA KITCHEN, BSN, RN, ALPHANET CLINICAL NURSE MGR.

As the temperatures drop and the cold winter months set in, here are some tips to help protect you against the blustery, chilly weather that lies ahead:

*Wood burning fireplaces pose risks for Alphas. Make sure your chimney is cleaned yearly and that the damper is open prior to using. Attempt to decrease the fumes/ashes that could irritate your breathing.

*Minimize exposure to breathing cold “icy” air by wearing a mask or covering with a scarf.

*Have your furnace inspected regularly. Pilot lights on gas heaters and stoves should be burning blue, not yellow or orange.

*As always, try to minimize contact with crowds this time of season as we are approaching the peak of the flu season.

* Practice good hygiene, wash your hands frequently and keep them away from your face.

*If you use oxygen, hide your oxygen (nasal cannula) inside your clothing. The cold temperatures can make your tubing cold and brittle! It will keep your O2 warm.

*Don't let the cold weather keep you away from family and friends. Bundle up and be safe out there!

More Alphas and Carriers Needed for New Research

New and exciting Alpha-1 research is on the horizon. To make it happen, the Alpha-1 Foundation Research Registry needs you!

The Registry is a confidential database of Alphas and Alpha-1 carriers across the country who are willing to participate in research. This can include something as grand as enlisting in a clinical trial to test new drugs – or something small, like filling out a survey.

We invite you to be part of finding a cure by joining the Alpha-1 Registry – and you can do that quickly and confidentially online at <http://tinyurl.com/researchregistry>. You can also call 1-877-886-2383 for a paper application.

CONGRATULATIONS!

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

May 2011: Brian Pelletier
Caribou, ME

June 2011: Katherine Hughes
Lynchburg, VA

July 2011: Tracy Mills
Haiku, HI

August 2011: Susan Marburger
Omaha, NE

September 2011: Diane Stowers
Kennesaw, GA

AlphaNet Welcomes New Board Member

AlphaNet is pleased to welcome newly-elected Board Member Miekeleen D. Koerth. Ms. Koerth is the Founder and CEO of MDK Consulting, LLC which provides strategy development and implementation planning consulting services to healthcare companies considering or executing new commercial models.

Ms. Koerth notes that she became involved with AlphaNet by chance. “I, like many non-Alphas, had not heard about Alpha-1, nor did I have any understanding of the disease progression and the challenges that patients and family members face until a current Board Member shared some background during a lunch conversation. After that discussion, I continued to do research, and began what I believe to be a predestined path to provide personal service and resources to the Alpha-1 community.”

Ms. Koerth received her Bachelor of Science Degree in Pharmacy from the University of Iowa. Currently, her community and personal involvement include The University of Iowa College of Pharmacy Executive Leadership Board, SCORE Business Consultant for Small Businesses Counselor, Orchard Owners' Association Board of Directors and, most recently, the Board of Directors of AlphaNet, Inc.

Ms. Koerth is proud to be a part of the Board, noting, “I look forward to helping define how AlphaNet can continue to invest resources effectively to provide the best possible care and support for the Alpha-1 community through my active participation with the AlphaNet Board of Directors. I cannot think of a better way to focus my volunteer time and energy.”





Susan Clarke joined the AlphaNet team as an At-Large Coordinator in June 2011. She lives in Hampstead, NH with her two sons, Gwilym and Gareth, and her three dogs and two cats.

Shortly after Susan moved to the States, she started to have problems with coughing. A little later, the coughing was accompanied by shortness of breath and wheezing and Susan's doctor diagnosed her with asthma. A CT scan ordered by Susan's doctor revealed that she had emphysema. This came as a shock to Susan who was a lifelong non-smoker. After researching emphysema, she asked her doctor if she could possibly have Alpha-1 — he dismissed this but referred her to a pulmonologist who confirmed that she had Alpha-1.

"I have come to terms with my diagnosis of Alpha-1, and am determined to maximize my potential. With certain adjustments, there is still so much I can enjoy."

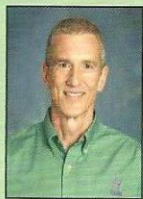


Angela Town joined the AlphaNet team as an At-Large Coordinator in June 2011. Angela lives in Guilford, CT with her husband Chris. Before she was diagnosed with Alpha-1, Angela experienced ten years of symptoms. She was diagnosed with asthma, allergies,

bronchitis and was even tested for heart issues. Angela had two bouts of pneumonia when her doctor looked through her records and immediately sent her for testing in 2006. She was found to be a ZZ.

Angela enjoys her role as a Coordinator because she has the opportunity to connect with Alphas on a personal level and form unique relationships based on mutual histories and shared experiences. "I love talking to fellow Alphas because I think it is so uplifting. I find that when I am talking to people, I attach what I speak about with them to my own life and discover similarities between us all—we all have families, friends and interesting stories to share."

Who's Who at AlphaNet?



Jesse Strickland joined the AlphaNet team in June 2011 as an At-Large Coordinator. He lives in Portsmouth, OH with his wife Pam.

Jesse was diagnosed with Alpha-1 in May 2008. Prior to his diagnosis, Jesse had asthma, allergies and frequent chest colds. He was told he had emphysema and was sent to a pulmonologist for Alpha-1 testing. Jesse's pulmonologist told him that he was an Alpha-1 carrier. Only after two years of going back and forth with doctors did Jesse finally get put on Prolastin. In May 2011, Jesse started an Alpha-1 support group in Ohio.

Jesse has compassion for Alphas and has learned a lot about the disease in such a short span of time. He is amazed by the support he has received, as well. "It's comforting to know you can reach out to someone for help if you ever needed it. Being part of AlphaNet feels like you are part of a large extended family — it's as if you've know everyone your entire life."



Peggy Iverson joined the AlphaNet team as a Zemaira Coordinator in October 2011. Peggy lives in Johnston, IA with her husband and one of her sons.

Peggy was diagnosed with Alpha-1 in 1975 when she was in her early 20s. She discovered she had Alpha-1 after her mother was tested at the Mayo Clinic and received her diagnosis. Peggy and her brother were then tested at the Mayo Clinic and Peggy was found to be a ZZ.

As a result of her early diagnosis, much of Peggy's life has involved Alpha-1, "For me, Alpha-1 has been a part of my life for all of my adult life. Because of that, I have had to make different choices so as not to compromise my health."

Peggy thoroughly enjoys her work with AlphaNet and notes, "I love talking with Alphas. I really learn so much from them and hopefully I am making their lives better by sharing what I know."

Determined Alpha Hikes to Soaring Elevations

Byron Kellogg isn't letting his Alpha-1 stand in the way of his outdoor pursuits. Kellogg, who enjoys hiking with his wife Joan around their Durango, CO home (elevation 6,940 feet), has discovered that with small adjustments to his lifestyle, he can still partake in outdoor activities even at high altitudes. With a little help from his portable oxygen tank and a lot of determination, Kellogg was recently able to hike to about 11,200 feet.

Kellogg, who was diagnosed with Alpha-1 in October 2004, took part in a trail hike in nearby Silverton, CO this past Fourth of July. The town of Silverton is an old mining town situated near the western edge of the San Juan volcanic field—in what is known as the Silverton Caldera—and is located at 9,318 feet above sea level.

Kellogg, armed with his 10 lb. portable oxygen tank backpack, set off to hike the Cunningham Creek Trail, which starts at an elevation of 10,750 feet and leads to the Highland Mary Lakes, located at an elevation of 12,100 feet. While Kellogg admitted that the hike was strenuous, he maintained that with the help of his supplemental oxygen, hiking at that elevation was actually quite feasible.

"I had an oxygen bottle that came in a backpack which I usually use to mow the lawn and do other strenuous activities around the home. Joan convinced me to try taking it on a high elevation hike to see how much it would help. It actually worked quite well."

Kellogg, who hiked with his wife Joan and his daughter Robyn, was able to make good progress on the trail until some bad weather forced

his family to turn around rather than continue their hike above the tree line. While they didn't reach the Highland Mary Lakes, Kellogg's portable oxygen tank proved to be invaluable on his trek and his "breathing test" was a success!

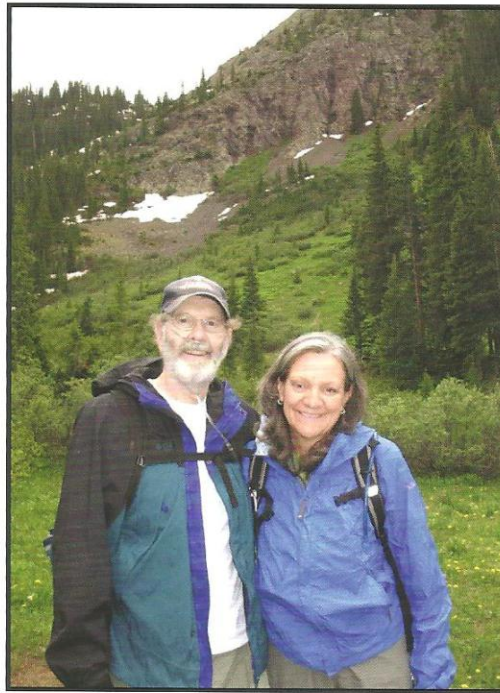
"I got up to about 11,200 ft. I was able to hike and turn around and not feel completely exhausted. I was able to maintain a fairly steady pace along the trail," Kellogg said.

The key to Kellogg's success on the trails is that he recognizes his breathing limitations and finds ways to work around his shortness of breath, which he often experiences when he participates in rigorous activities.

"By having the supplemental oxygen, I found that I could hike without much difficulty. Part of it is acknowledging your limitations and not being afraid to rest and take breaks. I take my time and try to avoid climbing hills too quickly."

At this point, Kellogg sees more hiking trips on the horizon, especially now that he has tested the utility and versatility of his portable oxygen backpack. He has found that he is no longer held back by his shortness of breath and can enjoy outdoor activities without great difficulty.

Besides his hike in Silverton, Kellogg visited Yosemite National Park for the first time in May 2011. While there, he hiked the Mist Trail to the top of Vernal Fall (elevation – 5,000 ft., elevation gain – 1,000 ft.). Additionally, he hiked several scenic trails around the San Francisco area in May.



Byron and his wife Joan take in the breathtaking scenery as they hike along Cunningham Creek Trail.

Alpha-1 Association Education Days

co-sponsored by the Alpha-1 Foundation

February 25
Phoenix, AZ

March 24
Birmingham, AL

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

January 14 - Houston Marathon
Houston, TX

March 10 - Celtic Connection
Boston, MA

April 14 - Alpha-1 Hero Walk
Richmond, VA

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. 248.

Your AlphaNet Coordinator is a great resource, whether you are a newly-diagnosed or long-time patient.

Take advantage of his or her expertise.

Check out "Questions to Ask Your Coordinator" and other FAQ's at www.alphanet.org.

STORY IDEAS?

Do you have an interesting story idea 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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