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The AlphaNetter

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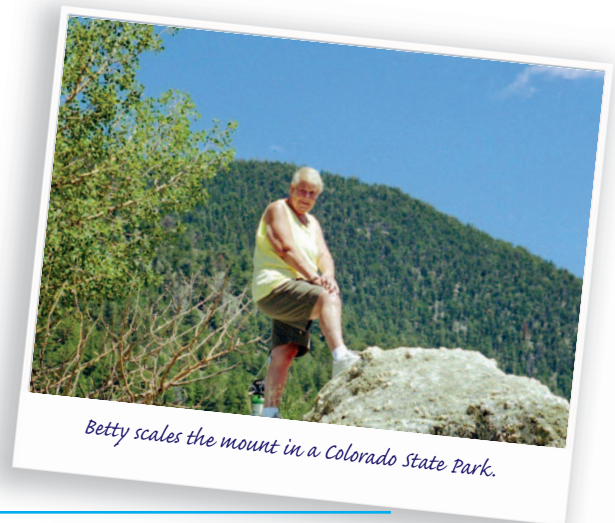
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Ohio Alpha Makes Every Second Count



One summer morning, Betty Klarowski got a call from her good friend and nurse Sherry Stewart, RN. This was not a typical health-related call, but rather a request for Betty to take off on a cross-country camping trip, later that same day.

Betty didn't hesitate, she quickly agreed, ran a few loads of wash, threw a few things together, gathered up her oxygen supplies and arranged care for her dogs and horses. They left at eight that same night for a three-week journey that took them out west through Colorado, a visit to Pikes Peak (with Betty at full tilt on her oxygen), Wyoming, Glacier National Park in Montana, the Dakotas and many other states before returning to the Midwest.

They covered 6,600 miles with infusions along the way and stops to exchange oxygen tanks. They had refrigeration in their pop-up camper for medical supplies and Apria Healthcare provided a booklet with store locations across the US to exchange oxygen tanks.

Betty, who runs a horse stable with her daughter (when she's not off having new adventures), has known Sherry for seven years, when Sherry began giving her home infusions.

In her spare time, Betty makes and sells unique backpacks to carry oxygen; as you might expect with a whimsical twist. Her designs include a horse, dolphin, bear, polar bear and lion and sell for \$39 each (contact Betty at bhab@adelphia.net). Each backpack also has ample room for keys and wallet.

Betty has also been on a river tubing trip recently. She simply packed her oxygen in a watertight pack and set off down-stream. As always, nurse/friend Sherry encouraged her. When Betty describes Sherry and their special friendship she explains, "God brought us together for a reason."

DOUBLE *Lung & Liver* TRANSPLANT SUCCESS

In the AlphaNet Family

AlphaNet is pleased to recognize some members of our current staff who are lung transplant recipients. Questions about transplants can be directed to your Patient Services Coordinator or any of these individuals:
Darrell Nall (At Large)
Mary Pierce (OH)
Doug Turley (IA, KS, MO)

In his late 30s, Richard Fallstich, electrical engineer and volunteer emergency medical tech, began noticing he was short of breath. Since he had been a smoker for years, he figured that was the cause and stopped smoking. But after a year, when he felt no better, he realized he'd better see a doctor. The resident of Fountain Hill, Pennsylvania, decided since he hadn't been to a doctor in years, he would consult his sister who worked in a local hospital emergency department. The internist selected immediately ran a number of tests, including the one for Alpha-1. He was diagnosed with Alpha-1 and later his sister was also diagnosed.

Richard was placed on Prolastin®* and with his wife and son it became their hope he might be a candidate for a lung transplant. Although still working regularly, Richard did not have much energy and sat at his desk all day, even eating his lunch there. Always optimistic, he was happy to still be productive. He thought he was at a low point when, just after Christmas, he went outside, took three steps from his house and had to call 911 from his cell phone because he could not move.

Then, during a 2004 hospitalization for a bout with pneumonia, his pulmonary specialist thought his bloodwork did not look right and called in a GI specialist. After extensive testing, it was determined Richard had cirrhosis (from the Alpha-1)

*Prolastin is a registered trademark of Talecris Biotherapeutics

and it was malignant. Apparently many of his respiratory symptoms had masked his liver-related problems. He was told he would not live more than a year with the liver cancer.

Discussions began for Richard to receive a rare multi-organ transplant including both his lungs and liver. In 2005, he became the third person to receive the complex transplant at the Hospital of the University of Pennsylvania.

"Now I feel better than I have in years, almost like I never had the disease to begin with," said Richard. "It might seem minor to most people but what I enjoy now are the everyday things others take for granted: going to a movie, a party, even doing the dishes."

He survived the waiting, one trip to the hospital that didn't result in a transplant due to unsuitable donor organs, 17 days in the hospital post-transplant surgery and months of rehabilitation. Richard says he, "will consider myself always an Alpha" and appreciates the continued follow-up calls he gets from his AlphaNet Coordinator.

All Transplant Centers are Not Created Equal

The Los Angeles Times reported, "about one-fifth of the nation's organ transplant centers do not meet federal standards for patient survival or perform the required minimum number of operations annually."

AlphaNet General Manager, Terry Young suggests Alphas and their families check the site: www.ustransplant.org for information and comparisons about transplant centers.

Richard Fallstich recommends that you be your own advocate, and coordinator of care. Follow-up, check on medication dosages, keep detailed notes and records. "You can't be passive, it's your life and your condition," said Richard.

FAMILY MAN WHO LOVES THE OUTDOORS

Bruce Galloway, from LaMoille, Illinois, has been hunting all his life. Now 46, he doesn't let his Alpha-1 diagnosis slow him down. Bruce enjoys all types of hunting and fishing, particularly spending time outdoors with his wife Wanda and two boys Barrett and Matthew. Currently, he is training a Beagle puppy named Briar Rose to be a good hunting dog. When he is not enjoying the woods and wildlife of Northern Illinois, Bruce spends his working hours operating heavy equipment for a cement company. One of ten children, Bruce was diagnosed 16 years ago and, after urging his family to be tested, has three siblings who also have Alpha-1.

Thanks!



Bruce and Briar Rose

NUTRITION

for Alphas

beyond the Big Fat Reference Guide

This article will attempt to impart some dietary tips that go beyond what you will find in the Big Fat Reference Guide. These tips have been culled from years of information gathering and trial by some of your most experienced AlphaNet Coordinators, Mary Pierce, Judy Rose and Liz Veronda and Robert A. Sandhaus, MD, PhD.

You may want to review this information with your physician and/or your AlphaNet Coordinator. AlphaNet is not endorsing or marketing any product mentioned in this article.

For a more complete discussion of nutrition in Alpha-1, visit the Big Fat Reference Guide on the web at www.alphanet.org



Much of our world revolves around food. We even have a cable TV channel devoted entirely to food, not to mention the overwhelming focus on food and diets in the rest of the news media, the controversy over too-thin models, and the blizzard of ads we see daily for fast food and food products. In short – food is news.

But what about food and Alphas? Can food help or hurt; does it ease breathing problems or make them worse? Unfortunately for Alphas it cuts both ways. Many are overweight and that may cause increased medical problems; yet others are working hard to maintain minimum weight as the disease puts such high demands on metabolism that the body just can't keep up. When the disease reaches a critical level, Alphas begin to lose weight without trying. It is important to tune in to a good dietary plan before extraordinary steps need to be taken to gain weight. Another consideration for many Alphas is that most transplant centers will not put you on their lists unless you are near ideal body weight.

OVERALL GOOD ALPHA NUTRITION:

- ❖ Eat whole, fresh foods, avoid processed foods whenever possible.
- ❖ Avoid fast food – but if you must go, eat the salads and grilled chicken, many now offer fruit and other healthier options.
- ❖ Fill a container of cut fresh vegetables at the beginning of each week to have an easy and healthy snack – you can even take it with you when you go out to lunch or dinner.

- ❖ Drink plenty of water (eight 8 oz glasses per day) and juices. Fluids help thin secretions and make it easier to cough up mucus. Go light on the juices since they often have sugar.
- ❖ Avoid or limit foods that cause heartburn or gas, bloating makes breathing more difficult.
- ❖ Eating several small meals throughout the day is easier on the digestive system, and uses less energy (leaving you more energy for breathing).
- ❖ Cured meats such as bacon, sausage and processed meats are high in nitrates and are more likely to impair lung function (“The Pulmonary Paper”, Sept/Oct 2006, *Respiratory News* column, from a report presented at the European Respiratory Society).
- ❖ Limit refined foods and sugars. Examples: white rice, white bread, mashed potatoes, pasta made from white flour, anything labeled “instant”. Refining removes the bran and most of the nutrients leaving very little of nutritional value. These foods force the body to focus on digestion instead of breathing. Instead choose brown rice, whole wheat breads and pastas and whole oatmeal.



- ❖ When they are available, fresh fruits and vegetables are best, but canned and frozen will substitute well in the off seasons.
- ❖ Organically grown fruits and vegetables and foods such as eggs, milk, poultry and beef may be of benefit, although they can be expensive.

LOSING WEIGHT:

The key is to move more and eat less. Many believe the Mediterranean type diets such as those touted by South Beach and The Zone can work well for Alphas. Many of the tips mentioned for gaining weight are good for you too, just carefully watch the number of calories you consume. Most people are amazed at how and where they consume calories during each day, so keeping a food diary is crucial to help you monitor and adjust your diet. You can buy a pocket calorie guide at most grocery stores (often at the checkout counter) or can do a web search on “calorie counts.”

- ❖ Portion control is key, have one plate of food at meals and no seconds.
- ❖ Essential fatty acids are good for you and they are found in foods such as avocados (and guacamole), fish oil, olives, walnuts and almonds
- ❖ Focus on more fruits and vegetables in your diet.
- ❖ Keep some low calorie snacks available.
- ❖ A sample breakfast would be some string cheese, apple and a handful of walnuts; or oatmeal; or an egg and slice of whole wheat toast.
- ❖ A great lunch would be a salad with spinach or romaine lettuce, cheese, sunflower seeds and a can of tuna, salmon or some chicken and an apple or grapes; a Caesar salad with chicken is an ideal lunch.
- ❖ There is some evidence that a cinnamon capsule a day can help smooth out the spike in blood sugar and help with weight loss.

GAINING WEIGHT:

This may be the biggest challenge for some. Food is fuel and when your body needs all the fuel it has just to breathe you have to struggle for enough calories to maintain weight. If you are underweight and have Alpha-1, gaining even one pound can take weeks of effort and near forced feeding. The trick is to slip in the additional calories wherever and whenever you can throughout the day. It may help to have a friend or family member prep meals in advance that can be frozen for use with minimal effort. Sometimes you are starving but too exhausted to eat. Check into Meals on Wheels in your area, maybe they can help.

- ❖ Be sure to use your oxygen and stay warm when you eat.

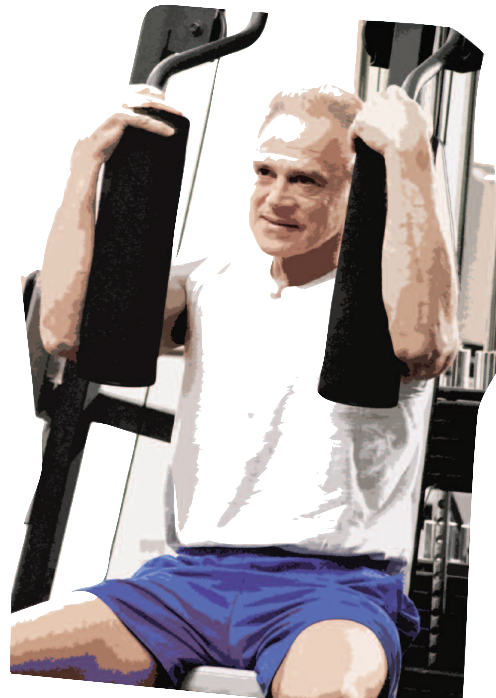
- ❖ Fish oil, fish oil, fish oil: (Try the big bottle of Omega 3 Fish Oil capsules from Sam's Club, ranked by Money Magazine as the best quality for the money). Fish oil is a natural anti-inflammatory, which can assist with the inflammation of chronic lung disease. Capsules are 1,000 mg each – take 3 – 4 daily. If you can't tolerate fish oil, substitutes may include flaxseed oil, evening primrose oil, borage oil or combination oils available in most pharmacies and health food stores.
- ❖ Whole grains are full of B vitamins and help keep your digestive system moving and healthy. Oat bran is known to reduce cholesterol. Fiber provides bulk to the digestive system and allows it to function more efficiently.
- ❖ Wash foods, cutting boards and food prep areas thoroughly. Keep dishwashing liquid in your kitchen hand soap dispenser to help cut grease and keep your hands clean. A fruit/vegetable-washing product can also be used.
- ❖ Take a good multi-vitamin and multi-mineral. Make sure it has ample amounts of the anti-oxidant vitamins C and E; flax seed oil or evening primrose is beneficial, along with vitamin C and the B vitamins. Your local health food store can help you make a selection.
- ❖ Keep a food diary for a week to see what you are actually eating.
- ❖ Most alcoholic drinks, including wine and beer, contain carbohydrates (sugars) and can harm the liver, and many doctors recommend Alphas with liver problems avoid it altogether. The way alcohol is converted once in the liver can effectively paralyze some of the liver's ability to process fats and sugars. If you do have an occasional drink, red wine is thought to be the healthiest option, but moderation is vital.
- ❖ Use plain yogurt, rather than pre-sweetened, and add your own fruit or fiber.



One good overall method to gain weight is with supplemental shakes. For example Scandishakes are used to help respiratory patients gain weight; this product is not high in carbohydrates, which are generally not good for individuals with respiratory problems.

- ❖ Scandishakes® (www.axcan.com/scandishake_us.php?lang=1 or call Scandipharm: 1-800-412-2634 to get a free sample), & weight gain powder (from the health food store); make a drink that is 2500 calories with 1 cup ice cream, a banana, 1- 2 cups of whole milk, 2 Scandishakes and 3-6 scoops of the weight gain powder. Keep in the fridge and drink this throughout the day.
- ❖ Other shake products that can be used, include Carnation Instant Breakfast®, Boost®, Boost Plus®, Ensure®, Ensure Plus® & Glucerna®. All can be enhanced as mentioned.
- ❖ Add olive oil, flax seed oil, or other oils, to foods (like cottage cheese) whenever you can.
- ❖ Use butter or margarine generously.
- ❖ Add peanut butter to toast, bread, crackers, banana slices, apple slices, or celery stalks.
- ❖ Add dry milk to hot cocoa, milkshakes, hot cereal, gravy, sauces, meatloaf, cream soups, or puddings.
- ❖ Add brown sugar to cereal or fruit.
- ❖ Go ahead and eat the real ice cream and the fruit with the heavy syrup.
- ❖ Add ice cream, whipped cream and nuts to pies and cakes.
- ❖ Add breading to meat, chicken and fish.
- ❖ Add a supplement such as MCT Oil (medium chain triglycerides). This is expensive and should be used upon the advice of a physician or dietitian.
- ❖ After a meal, sit for at least one hour and let the calories absorb into the body.
- ❖ Eat before you go to bed, so the calories can absorb while you are at rest.

There is a great book: “Dr. David Reuben’s Quick Weight-Gain Program” that has good recipes and tricks to help this process.



This book may be out of print; try www.amazon.com for used copies.

Contact Mary Pierce or Judy Rose for more information about weight gain.

EXERCISE IS CRITICAL FOR ALL ALPHAS:

We can't talk about nutrition and not mention the importance of exercise. Because lung disease can make it even harder to keep doing routine activities, alphas need to retain and build strength and stamina.

Start today with a promise to yourself that, no matter how bad it feels at first, you will take a few extra steps, do a few leg lifts or climb a few steps. Ask your doctor to prescribe pulmonary rehab or join a gym where you can do strength training and/or aerobics. Another option might be chairbotics (www.chairbotics.com).

Alphas come in all shapes, sizes and conditions and must craft a plan that is very individualized. Call your coordinator for help and inspiration: you can do it.

WEBSITES ABOUT NUTRITION AND RELATED TOPICS:

www.MyPyramid.com

www.healthinaging.org/public_education/eldercare/3.xml

www.mayoclinic.com/health/cancer/HQ01134

www.medicaring.org/educate/download/copdbookfinal.pdf

www.sciencedaily.com/releases/2003/02/030205073358.htm

CINNAMON: www.aolsvc.health.webmd.aol.com/content/article/78/95675.htm

GAINING WEIGHT: www.howtodothings.com/health-and-fitness/a3482-how-to-gain-weight.html

IDEAS FROM THE CYSTIC FIBROSIS WEBSITE: www.cystic-f.org/handbook/html/nutrition.htm#SupplementalHome

Did You Know ...

Barometric Pressure changes can affect our breathing because the air that is normally trapped in lungs expands as the barometric pressure drops and contracts when it rises. It has been reported

to be quite common to hear Alphas say "There must be a storm coming, I'm feeling a little tighter." Or, "Every time it storms, I get more short of breath."

Barometric pressure also changes with altitude. At sea level, **oxygen makes up 21% of the air we breath.**

For example, if an individual travels from sea level to the mile high city of Denver, the percentage of oxygen in the air drops to the equivalent of 19%. Air travel and/or higher locations (like Denver), result in an even lower percentage of oxygen levels. Keep in mind, when local weather forecasters report changes in the barometric pressure they are reporting the changes for their specific location.

– information provided by Robert A. Sandhaus, MD, PhD

ALPHA-1 EDUCATION DAYS:

- April 14 Pacific Medical Center & COPD Foundation
COPD/Alpha-1 Education Day
San Francisco, CA
 - April 28 St. Luke's Roosevelt Hospital
Alpha-1 Education Day
Engelwood, NJ
 - May 6 Regional Support Group Meeting
Portland, OR
 - May 12 University of Minnesota, COPD Foundation
COPD/Alpha-1 Education Day
Minneapolis, MN
- To find out more about conferences and support groups, visit the Alpha-1 Association website at www.alpha1.org

ALPHA-1 EVENT CALENDAR:

- April 12 Crazy Bowl, *IL*
- May 4 Knockout Alpha-1: Celebration of Life
Miami, FL
- May 10 Mother's Day Scarf & Card, *USA & Abroad*
- May 18 Alpha Okies Silver Horn Golf Event
Oklahoma City, OK
- June 2 Fisherman Invitational Tournament
Key West, FL
- June 8 Find a Cure Car Magnets, *USA & Abroad*
- June 17 Father's Day Ties, *USA & Abroad*

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