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The AlphaNetter

Healthy Eating May Lead to Healthier Alphas

By: **Bonnie S. Boyd, BS, RN, Director of Disease Management & Clinical Research**

While eating well should be a priority for everyone, a balanced diet can be especially important for Alphas as it may lead to notable changes in their overall quality of life.

The Big Fat Reference Guide — commonly referred to as the BFRG — notes that, “Good nutrition may help Alphas to protect lung function and improve breathing by providing the energy and muscle tone needed to maintain effective respiratory effort. A poor diet can complicate Alpha-1 by imposing additional problems associated with diseases such as hypertension, coronary artery disease, diabetes and others.” That being said, here are some helpful dietary recommendations for Alphas found in the BFRG that are “based upon the current knowledge of Alpha-1 and the principles of sound nutrition as described by experts”:

- **Maintain a well-balanced diet.** Your caloric intake should consist of 15 percent protein (lean meats, poultry and fish), 30 percent fat (nuts, olive oil) and 55 percent carbohydrate (fruits, vegetables and whole grains).
- **Consume a variety of grains daily — especially whole grains.** Strive to eat one of the following at each meal: whole wheat bread, brown rice, cornmeal, bulgur, whole wheat pasta, whole wheat crackers and whole grain cereals like oatmeal.
- **Eat a variety of fruits and vegetables.** Eat a serving of fresh or frozen fruits and vegetables at each meal.
- **Choose a diet low in saturated fat and moderate in total fat.** Limit your daily consumption of high-fat meats, butter, whole milk and cheese. Instead, replace these with lower fat options of these foods such as lean meats, low-fat milk and reduced-fat cheese.
- **Choose beverages and foods to moderate your intake of sugar.** To keep sugar from displacing foods with nutrients, set a daily intake limit for sugar of no more than 10 percent of the total calories. Essentially, this means that dessert foods such as ice cream, brownies and candy, as well as sugary beverages such as sodas and fruit drinks should be consumed sparingly.
- **Limit overall sodium intake and prepare foods with less salt.** Do not add salt during food preparation or to food served at the table. Minimize the consumption of packaged and processed foods. Rather than buying frozen entrees, which are often loaded with sodium, choose to eat fresh meats, whole grains, and fresh or frozen fruits and vegetables.

For additional information about healthy eating, consult the BFRG. The full version is available online at: <http://www.alphanetbfrg.org>.

Husband of Alpha Runs for the Cause

While Chip Trahan has been running recreationally for several years, little did he know that what began as a pastime would transform into something much more meaningful. Chip, who lives with his wife Jennifer in Houston, Texas, completed his eighth marathon this past January. This race, however, was quite different from all the previous ones he had participated in because on this occasion, he was running for Jennifer, who is an Alpha.

Jennifer was diagnosed with Alpha-1 in 2008. Just before she was due to have a routine surgical procedure for an unrelated medical issue, the anesthesiologist came into the operating room and inquired as to whether Jennifer had ever been informed of the spot on her lungs, which had appeared on an X-ray. Upon hearing this startling news, Jennifer and Chip immediately took action to figure out exactly what was wrong. After visiting several pulmonologists, Jennifer was told she had emphysema based on CT scans. Following this diagnosis, she was given blood tests which confirmed that she was a ZZ Alpha. Interestingly enough, while Jennifer's father had been diagnosed with Alpha-1 in the 70s, she was not aware that she needed to be tested, because at the time, public awareness of Alpha-1 was virtually nonexistent.

Armed with the knowledge that his wife had Alpha-1, Chip sought out ways to get involved with Alpha-1 awareness as he admits that he often felt helpless throughout the long process of getting Jennifer properly diagnosed. "I went to all the doctor visits and witnessed all the emotions she experienced from the very beginning and there was little I could do for her other than provide emotional support," Chip said.

While researching online, Chip discovered that he could raise money for Alpha-1 by participating in marathons. He welcomed this idea, as he had been running regularly for the past several years. "I felt like I was on the sidelines when it came to Jennifer's Alpha-1 so this was just another way to show my support for her."

In order to drum up interest for the cause, Chip created a Facebook page, "I Run for Alpha-1" and chose to use the nonprofit fundraising website *FirstGiving* to raise money for Alpha-1 research. In the meantime, Chip

also began training for the Houston marathon about five months prior to the January race date. He ran mostly indoors on the treadmill during the weekdays, usually about eight miles or so. On the weekends, Chip would train outdoors, running anywhere from 12-17 miles. Oftentimes, Jennifer joined Chip on his outdoor runs but would walk, rather than run.

The response to Chip's Facebook page and to his charitable donations website on *FirstGiving* was overwhelmingly positive. From the very beginning, one of his main goals was to raise awareness for Alpha-1, and his Facebook page accomplished that in so many ways. He notes, "Jennifer and I have met so many people in the Alpha-1 community as a result of the Facebook page. I would estimate that roughly half the people that follow us on Facebook are Alphas and the other half are family members of Alphas and individuals who are just interested in learning about the disorder. We have communicated with people from London, Iraq and even Australia. One

comment that we received over and over again was, 'It is so good to hear people talking about Alpha-1.'"

As a result of the Facebook page and his *FirstGiving* charitable giving website, Chip raised nearly \$2,000 in donations for the Alpha-1 Foundation. On January 15, Chip completed the Houston Marathon with an impressive time of 3 hours and 44 minutes.

Although the race has ended, Chip and Jennifer, who participates in AlphaNet's Step Forward Study, have found creative ways to keep active. In order to get Jennifer motivated to exercise, Chip instituted "Commercial Workouts." Essentially, when Chip and Jennifer watch a television program in the evening, they perform some sort of exercise every commercial break throughout the entire show. "I do sit-ups or push-ups and my wife usually does yoga and stretching. It lasts about an hour but it has worked out well. It really opened the door to doing more exercise—Jennifer now does yoga some mornings and I still run."

As for the future, Chip is eager to participate in the 2013 Houston Marathon and wants to get the "I Run For Alpha-1" Facebook page updated, as well as generate new contributions through his *FirstGiving* donation website.



Chip runs in marathon for Alpha-1.

Alpha Maintains Good Health With Active Lifestyle

As summertime approaches, Alpha Laurie Walker is gearing up to log hundreds of miles over the course of the next several months as she bikes around her St. George, Vermont hometown. Laurie, a retired registered nurse, and her husband Bob started cycling in 1999, initially biking on scenic wooded paths adjacent to their home and then dirt roads.

When Laurie first began riding, she had not yet been diagnosed with Alpha-1. She did, however, notice that she was oftentimes at the back of the pack and wondered why she couldn't keep up with her fellow cyclists. "My heart rate would go up really high. That was my first indication that something wasn't quite right. I began wearing a heart monitor when I rode in order to keep it in a decent range and I would slow down the minute I noticed my heart rate was climbing too high."

While Laurie had yet to be tested for Alpha-1 at the time, she was aware of the disease, as her younger sister had previously been diagnosed and had strongly urged Laurie to get tested. She finally did so in 2004 and the results indicated that she did, in fact, have Alpha-1. "When I was tested I was convinced that the doctor had mixed up the results because I was still biking and was very active."

With Laurie still in disbelief about her diagnosis, she enrolled in a sibling study with her younger sister where they performed blood and spirometry tests on her and her parents. She finally went to see a pulmonologist, who ordered a high-resolution CT scan. The scan revealed that she had mild diffuse bronchiectasis throughout her lungs and the presence of emphysema. In April 2005, following this diagnosis and knowing that she had also previously been diagnosed with Alpha-1, Laurie finally began augmentation therapy.

Laurie certainly has not let her Alpha-1 stand in

the way of her love of cycling and other outdoor activities. Over a decade after they began cycling, Laurie and Bob can still be found riding along the dirt roads surrounding their Vermont hometown. Last summer, they

logged an impressive 1,500 miles each of bicycling.

Additionally, last fall Laurie biked around Cape Cod with her college girlfriends. "Every fall, we organize a trip—usually biking trips. This fall, we will be hiking in Utah and we will do some biking, as well, in Zion National Park," Laurie said. She also spends several months during the year skiing with Bob in Lake Tahoe and other Nevada and California ski destinations.

When it comes to exercise, Laurie has found that by simply adjusting the way she rides, skis and hikes, she really can participate in most outings with relative ease. "When I first started biking, it was agony to bike on the hills. All you have to do is add a backpack when hiking, or go up steep hills biking and I know I have Alpha-1. I do have to go slower and I'm careful of what I carry on my back. I have to pace myself and I use lower gears to

keep me from getting winded."

Laurie finds that even though some days she lacks the motivation to exercise, she oftentimes is able to muster up the mental and physical strength because she knows the outcome will be worth it. "Sometimes when I really don't want to go, I convince myself that I should because I know I will feel better once I am biking with Bob."

Laurie looks forward to biking more now that the weather is becoming warmer and she hopes to return to Canyonlands National Park in Moab, Utah where the terrain is a bit flatter and, therefore, easier on her lungs. She will also continue to ski and notes, "Bob and I will ski until we can't get down the mountain." With that determination, it is clear that Laurie has no plans to ease up on her active lifestyle any time soon.



Laurie bikes around her Vermont hometown.



Bob and Laurie ski in Heavenly, Lake Tahoe, California.

Stretch, Lift and Walk: Exercise Tips for the Active Alpha

Now that you have hung up your winter coats and stored away your cold weather gear for the season, it is an ideal time to jumpstart an exercise regime. While incorporating healthy eating habits into your daily life can lead to positive changes, exercise is also a key component to overall improved health. According to the BFRG, “Routine exercise can help: control blood sugar levels, increase muscle strength and endurance, promote improved joint function, boost the immune system to fight infections, decrease the risk of developing heart disease, improve energy levels and strengthen the bones.” For Alphas, in particular, exercise can be especially beneficial as it “can improve endurance, breathing efficiency and dyspnea (shortness of breath) tolerance.”

The BFRG provides the following general recommendations regarding an overall exercise program; however it is important to note a few key points. You should always consult your physician before beginning any exercise regime to obtain a medical evaluation for cardiac risk and exercise capacity. Be aware that there are many more exercises in each category than space allowed for in the BFRG, so choose an exercise that works best for you. Central to all exercise programs is that they be done in a safe and effective way so as to prevent injury and ensure that you are not exerting yourself beyond your fitness capacity. This is easily accomplished by using exercise monitoring methods described in the BFRG. New exercise programs should begin at lower intensity levels and progress to more intensive levels based upon this monitoring. Each exercise and workout recommendation below should be evaluated and, if needed, modified according to your individual ability, personal fitness level and current health status:

- **Flexibility Training:** Flexibility exercises include: calf and quadricep stretches, as well as hip and hamstring stretches. As far as frequency is concerned, five times per week is recommended. Hold each stretch for 10 to 30 seconds.
- **Muscle Strengthening:** For lower extremity strength training, exercises such as straight leg raises, hip sidekicks and modified knee bends are recommended 3-4 times per week “to combat muscle weakness that contributes to activity limitations such as in walking.” For upper extremity strength training, incorporate small hand weights (ranging from ½ lb to 2 lbs) into exercises such as weighted arm raises and standing arcs. These should be done in two-minute intervals with one minute rests in between for a total of 15 minutes. Strength training involving weights should be done 3 times per week—ideally, every other day in order to allow muscles to rest.
- **Cardiopulmonary Endurance Training:** As far as cardiopulmonary exercise is concerned, this type of activity can be accomplished using a variety of different methods including a stationary bike, treadmill or simply by walking outdoors. The BFRG notes that, “Unless otherwise advised by your health care provider, your training sessions should be approximately 20 to 30 minutes in duration,” and should occur 3 -5 times per week.

For further examples and more in-depth instructions on how to properly perform any of the listed exercises, please consult the BFRG or the “Exercise” Skinny Little Reference Guide. The complete version of the BFRG can be viewed online at: <http://www.alphanetbfrg.org>.

Clinical Corner

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

With the warmer months quickly approaching, now is a great time to focus on fitness and healthy eating. While there is an abundance of information available regarding healthy eating, it can be quite overwhelming trying to sort through all the facts — particularly for an Alpha who may be having enough trouble simply trying to breathe! Breathing for an Alpha can use up to 10 times more calories than a person without Alpha-1. With that in mind, Alphas need to be especially mindful of what they eat so they can make certain that they are receiving enough vital nutrients to keep their body properly fueled. Try these easy and basic tips to better nutrition:

- **Eat small frequent meals-** When you're short of breath, eating a large meal is difficult. Try to eat every few hours throughout the day. A small, frequent meal is definitely a more comfortable way to eat.
- **Healthy snacks-** Try to avoid junk food and opt for healthy snacks that are easy to prepare instead. Such items as granola in yogurt, dried fruits, fresh fruits or almonds would be great choices.
- **Eat your veggies-** Just like mom used to tell us. Try to consume 6 to 7 servings a day. Watch for the hidden sodium (salt) intake in canned vegetables. Try to eat fresh vegetables that are in season whenever possible. Try a hearty salad for lunch or dinner with many colors of vegetables tossed in for flavor.
- **Protein-** Your body needs protein to repair and maintain itself. Some great examples would include beans, lean cuts of beef, pork, fish or low-fat cheese.
- **Exercise-** Participate in at least 30 minutes of exercise or strength training each day— if your health allows. This will help decrease depression and increase your metabolism. It's a win-win!

Remember, good nutrition and exercise help the body fight infections!

Healthy Spring Salad

Serving Size: 2

- | | |
|---------------------------|--------------------------------|
| 5 cups of romaine lettuce | ¼ cup unsalted sunflower seeds |
| ½ cup chopped celery | ¼ cup balsamic vinegar |
| ½ cup chopped tomatoes | ½ cup extra virgin olive oil |
| ½ cup sliced cucumbers | ½ teaspoon black pepper |
| 3 grilled chicken breasts | 1 lemon |
| ¼ cup dried cranberries | |



Cut grilled chicken breasts into bite-size portions and set aside. Next, chop romaine lettuce and, in a large bowl, combine all ingredients except for olive oil, balsamic vinegar, lemon and pepper. In a separate small bowl, combine balsamic vinegar, the juice of a lemon and ½ teaspoon of black pepper and stir. Whisk together dressing ingredients and begin pouring oil slowly into the mixture. Continue whisking until dressing is thoroughly mixed. Drizzle dressing, as desired, over the ingredients in the large bowl and mix well so the dressing evenly coats the salad. Serve and enjoy!

Alpha-1 Association Education Days

co-sponsored by the Alpha-1 Foundation

June 8-10
Seattle, WA (National Education Conference)

August 18
Lebanon, NH

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

June 23 - Get the Scoop on Alpha-1
Minneapolis, MN

July 28 - Get the Scoop on Alpha-1
Johnston, IA

September 28-30 - Team Alpha-1 Escape
to the Cape
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. 248.

CONGRATULATIONS!

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

October 2011: Erle Oman
Ogden, UT

November 2011: Lennis Mosley
Kissimmee, FL

December 2011: Judith Gibbs
Watkinsville, GA

January 2012: Charles Frost
Vienna, VA

February 2012: John McCormick
Mesa, AZ

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.