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The AlphaNetter

In Memory of Bonnie S. Boyd



Bonnie S. Boyd, 65, died Sunday, September 25, 2016 at her home in Lake Worth, Florida. Bonnie served as an integral member of the AlphaNet medical staff for over 15 years as the Director of Disease Management and Clinical Research.

“Bonnie was instrumental in creating, writing and producing the *Big Fat Reference Guide*, our nursing education videos, the ADMAP program and our clinical trials. She will be sorely missed by our board members, staff, AlphaNet Coordinators and all who knew her,” AlphaNet President and CEO Robert C. Barrett said.

During her time at AlphaNet, Bonnie was devoted to the Alphas she served and facilitated numerous clinical trials to advance Alpha-1 research. “She was always diligent in making sure that the health and wellbeing of our patient community was put at the forefront of all we did. She was available at virtually any time of the day or night to help a patient, help a coordinator, help a clinician or help a friend,” AlphaNet Medical Director and Executive Vice President Dr. Robert A. Sandhaus said.

Prior to working at AlphaNet, Bonnie served as the Vice President and Chief Nursing Officer at Tenet St. Mary’s Medical Center in West Palm Beach, Florida. Her previous work included over 13 years as a Nursing Director with clinical experience in critical care, cardiovascular disease, trauma and emergency medicine.

Bonnie is survived by her mother Donna Longcore, sister-in-law Julie Longcore, nephews Larry and Bryan Longcore, three great nephews and one great niece.

Alpha Walks Her Way to Improved Health

Alpha Jan Moore shares her inspiring story of how she took control of her Alpha-1 diagnosis and lost 65 pounds in the process.

In 2009, Alpha-1 presented itself to me in a most dramatic fashion but, as I look back, that was not really the beginning of my story. I had been symptomatic since the age of 17. In August 1971, I noticed both of my upper arms had small open sores right above the elbows. I was diagnosed with a staph infection, started penicillin and was monitored weekly. After 6 weeks, my sores healed and so ended the doctor visits. Between 1971 and 2009, I had several upper respiratory infections, four of which turned into pneumonia, and many diagnoses of bronchitis. As a high school teacher for 37 years, I attributed these afflictions to sick students coming into my classroom. In 2000, I was diagnosed with asthma and given a bronchodilator to use.

In August 2009, my life changed forever. After eleven weeks in the hospital, with eleven biopsies of seeping skin lesions, having 23 liters of fluid drained from my lungs during 7 lung taps and a chest tube, 100% supplemental oxygen, numerous IV antibiotics, and a plethora of scans, X-rays, scopes and tests by many teams of doctors, I was finally diagnosed with Alpha-1 Antitrypsin Deficiency.

I am one of few Alphas that is skin affected with fifteen lesion scars from panniculitis, lung affected with COPD and liver affected with stage 3 cirrhosis. This was hard for me to take because I, just like many non-Alphas, believed only smokers got COPD and alcohol drinkers got cirrhosis. I was very confused because I have never smoked and have never consumed alcohol.

Once I got home from the hospital and started augmentation therapy, my health began to improve, but I had to come to terms with the fact that I had to create a new normal. I had to retire from teaching because it became so physically demanding. My husband, who was my caregiver and my rock, also retired from teaching to take care of me. After retiring in 2013, we moved closer to my family and specialists. My Alpha-1 diagnosis was life-changing for me, but it was not the end of my world.

My husband and I became regular mall walkers to try to improve my lung function. Having been overweight for 39 years, I hoped that walking would also help me lose weight. It didn't, but I was breathing better, so we made walking a part of our daily routine. We also were able to

attend support group meetings on a regular basis.

My AlphaNet Coordinator frequently recommended pulmonary rehab as something that could help. When I mentioned it to my pulmonologist, he said I did not need it. He was my first pulmonologist — the same doctor who had never ordered a pulmonary function test or a sleep study to test my oxygen flow at night. I stayed with him for two reasons: 1.) I didn't know any better and 2.) he said he had studied Alpha-1 in medical school.

In November 2014, I told my husband that I needed to do something about my weight. Walking at the mall was making me feel good but wasn't helping me lose weight. I talked with my primary care doctor and he recommended that I visit a weight loss center. That was probably the hardest phone call for me to make because I would have to admit I was obese and needed help. One of my motivators was an upcoming trip to Germany.

With the onset of a new year, I started my new diet, along with pulmonary rehab twice a week and walking in the mall at least 3 times a week. As an additional motivation tool, I got a device that counted my daily steps. Once I began to feel good about the improvement I was making in breathing and the weight I was

losing, I challenged myself to do even more. One thing that really helped was that my daughter Aimee and her husband Rich had become runners so they would challenge me each day to a certain number of steps. I am so competitive that I could not back down from those challenges, which pushed me even more.

With the encouragement of my family, medical professionals, friends and my AlphaNet Coordinator, I have not only lost 65 pounds but I am also off all supplemental oxygen. I feel great and am able to do things I have not done for many years. In the past I would avoid stairs at all costs; now I take them instead of elevators or escalators because I can. When out shopping, I look for the parking spot farthest from the door so I can add more steps. I used to dread the words "more steps" but now these words put me closer to my goal and, on many days, over my goal of 12,000 steps. It has not been easy, but it has been productive and, due to my competitiveness, it has been fun. I have created a new normal for myself and work every day to improve and change that normal for the better because I have Alpha-1 Antitrypsin Deficiency *but* it does not have me.



Jan Moore after completing a 5K race

Vaccine Considerations for Alphas

Why should Alphas consider vaccinations/immunizations?

Preventing damage to your lungs and liver is critical to maintaining your health. Vaccinating to avoid diseases that could damage your lungs or liver is wise.

Which vaccines should Alphas consider getting?

The Annual Flu Shot – The flu virus is constantly evolving and, as such, your immunity declines so it is necessary to get a shot every year to be protected. Those in North America should usually get a shot by October to be protected for the typical flu season. The type of flu shot varies by age. The nasal spray form is a LIVE vaccine and should be avoided by those who have lung disease or have had an organ transplant.

Pneumonia Vaccine – The PCV13 vaccine protects against 13 types of pneumococcal bacteria and the PPSV23 vaccine protects against 23 types. The Department of Health and Human Services currently recommends that children and adults at increased risk for pneumococcal disease get one dose of PCV13. This includes children and adults with various conditions including asthma, lung disease, organ transplant and cirrhosis. People with Alpha-1 lung disease should receive PPSV23, as well, and a second dose of this vaccine after 5 years. One year should elapse between taking the PCV13 and PPSV23 shots.

Whooping Cough (Pertussis) – Because it is a respiratory illness, it is a good idea for Alphas to get protected from whooping cough. Children receive a series of DTaP shots and adults can have a Tdap booster. Pregnant women should discuss with their doctor having a shot to protect the baby.

Hepatitis A and B – These vaccines are recommended for all those with Alpha-1 since hepatitis is a known risk factor for the development of liver disease in Alpha-1. Both vaccinations require a series of shots.

Shingles – The CDC recommends this vaccine for those over 60 years old who have chronic liver disease. It is a LIVE vaccine and should be avoided by those who have had organ transplants.

Where can I get vaccinated?

Your primary care doctor gives vaccinations. Some pharmacies can provide certain vaccinations for a fee. Additionally, free vaccinations are often offered by county departments of health to children or to all ages in response to local flu outbreaks. The federal government offers the following tool to find other locations in your zip code that offer vaccinations: <http://www.vaccines.gov/getting/where/index.html>.

After a transplant should I get vaccinated and is it safe for my family to get vaccinated?

Anyone who is immunosuppressed, taking anti-rejection drugs or receiving certain medications that modify your immune response, such as new drugs to treat rheumatoid arthritis, inflammatory bowel diseases and psoriasis, need to take special care when considering vaccinations. For instance, after a transplant, you and your family should avoid LIVE vaccines which can pose an infection risk; instead choose “inactivated” vaccines. Vaccination is important but must be done carefully after a transplant or under the circumstances mentioned above. Because your situation is unique, it is imperative that you discuss immunization choice and timing with your doctor.

Warning: The Measles, Mumps and Rubella (MMR), Chicken Pox (Varicella), Shingles and the nasal spray form of the flu vaccine are all LIVE vaccines and pose a risk to post-transplant patients. If you or your children will be visiting someone who has had a transplant, be aware that being around a person who has had a LIVE vaccination within the last 8 weeks can be dangerous for an immune compromised person. Consider children’s vaccination schedules when visiting relatives who have had a transplant.

Oral Hygiene Important for an Alpha's Overall Health

Good oral hygiene is a very important component of a disease management and prevention program, especially for Alphas. The reasons for maintaining good oral hygiene are much more than cosmetic. While at one time it was believed that the worst outcome of gum disease was tooth loss, studies have shown that oral health affects the entire body. Bacteria that are present in the mouth, particularly from decaying teeth or infected gums, can easily enter the bloodstream and migrate throughout the body causing damage to the heart, lungs and other organs.

Recent research suggests that the bacteria found in the mouth and throat can be drawn into the lower respiratory tract and cause infections in the lungs and bronchial tubes. The human mouth always contains some bacteria, but the presence of dental infections of any type can increase the number of harmful bacteria and lead to the growth of new bacteria that are particularly hard to treat if they cause infection in the lungs or airways. With proper oral care, however, gum disease can be controlled or even reversed.

Visiting your dental hygienist on a regular basis is one of the most important steps you can take to maintain or improve your oral health. Your dental hygienist will review your medical history, clean and polish your teeth and refer any areas of concern to your dentist or physician.

Developing a good daily oral cleaning regime, along with routine visits with a dental hygienist, will often control or reverse gum disease. Less than five minutes, twice a day, is all it takes to maintain or improve oral hygiene:

- **Brushing:** Place your toothbrush at a 45-degree angle to the junction between tooth and gum, applying gentle pressure as you move the brush away from the gums. Don't forget to brush your tongue, where bacteria build up. You should brush for about three minutes each time.
- **Flossing:** Wrap 18 inches of floss around your middle fingers until you have a two-inch length between them. With the thumb and forefinger of each hand, guide the floss gently and carefully between each tooth in a "C" shape and gently guide it up and under the gum line.
- **Antibacterial mouthwash:** In addition to the steps above, some dentists advocate the regular use of antibacterial mouthwash, particularly during cold and flu season. Consult your dentist or dental hygienist to see if this is recommended for you.
- **Dentures:** Even if you wear dentures, it is still important to clean your mouth and get regular dental check-ups to prevent oral health problems.



Clinical Corner

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

Making Your Home Allergy Safe

One way to find relief from your seasonal allergies is to try to avoid the things that aggravate them. If you can make your home, especially your bedroom, allergen-free (or at least reduce allergens), and take other steps to avoid allergens in your daily activities, you can live with your allergies more easily.

Here are some tips to help you reduce allergens in your home:

- Install an air filter in your forced air heating and/or cooling system.
- Change your clothes and shower when you come in from the outdoors (Pollen sticks to your hair and clothes and continued exposure can aggravate your symptoms).
- Leave your shoes at the door (Pollen and mold can be tracked in from the outdoors via the soles of your shoes and can continue to aggravate your symptoms).
- Keep pets out of the bedroom and especially off the bed. In addition to dander and dust mites, pets carry pollen grains in from the outdoors.
- Wash all bed linens, including pillows, in hot water—at least 130 degrees Fahrenheit—to remove dust mites.
- Avoid raking leaves or mowing lawns, which stirs up mold.
- For mold allergies, use a dehumidifier in damp areas and do not sleep in basement-level areas.
- Avoid having indoor plants; mold grows in wet soil.



Did You Know?

Men, not just women, need to pay attention to their bone health. Medical experts have recognized several risk factors that increase the likelihood that men will develop osteoporosis. They include: being more than 56 years of age, less than 175 pounds and suffering from COPD.

Smoking, excessive drinking and certain prescription drugs, such as steroids and those used for prostate cancer, can also put men at higher risk for the bone disorder. Good nutrition, calcium, vitamin D and exercise can all help reduce the risk of osteoporosis.



Alpha-1 Foundation Education Days

October 29
Charleston, SC

To find out more about education days and support groups, visit the Alpha-1 Foundation website at www.alpha1.org or call toll-free: (888) 825-7421, ext. 331.

Alpha-1 Foundation Events Calendar

Oct. 22 – “Strickly” Alphas 2nd Annual Walk
Portsmouth, OH

Nov. 1 - 30 – The Virtual Walk allows you to walk anywhere, anytime during the month of November in support of Alpha-1 awareness! You can join as an individual or register an independent team. Interested in adding your scheduled walk under your state? Let us know by emailing Angela McBride at amcbride@alpha1.org.

To find out more about these or other events in your area, log on to www.alpha1.org or call toll-free: (888) 825-7421, ext. 233.

For Your Information...

Your AlphaNet Coordinator is a great resource, whether you are a newly diagnosed Alpha or a long-time AlphaNet subscriber. Take advantage of his/her expertise.

Check out the “**Questions to Ask Your Coordinator**” pamphlet and other FAQ’s at www.alphanet.org.

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.

