



Summer 2011

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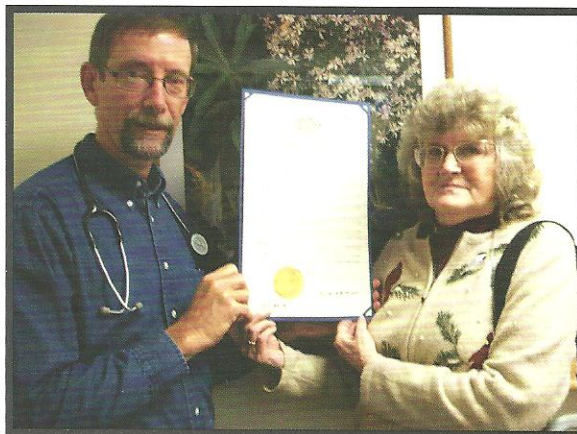
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The AlphaNetter

The AlphaNetter is a publication of AlphaNet, Inc.

Alice Dunkley approaches life with a decidedly simple mindset. "I don't have time to be sick," she asserts. At age 36, and after 20 years of smoking, Alice was told that she had lost 25% of her lung volume. She quit smoking and hoped her lungs would maintain and possibly even improve. Five years later, however, she discovered that she has lost 60% lung function. A lab test confirmed that Alice had inherited Alpha-1 Antitrypsin Deficiency. At the age of 42, Alice was told she should forgo making any retirement plans and, instead, should shift her focus to planning for the 2 to 5 years of productive life she likely had left. With this prognosis, Alice decided to complete her associate degree, which she did in 1992, and graduated cum laude. Those 2 to 5 years quickly turned into 15 and then 20, and, throughout this span of time, Alice learned to cope with her Alpha-1 diagnosis.

Alice, like so many Alphas, has had to make certain life adjustments. She recently found a new personal oxygen system and oxygen therapy eyeglass frames to help her in maintaining her health goals. These innovations in oxygen therapy have made it easier for Alice to



A Fellow Advocate

about both diseases to the Alpha-1 and COPD communities. Three years ago, Alice became a volunteer for the COPD Foundation call-line. Last November, she received a proclamation from the New York state governor's office for her efforts in promoting COPD and Alpha-1 awareness. Dr. Dan Way—the physician who diagnosed her Alpha-1 and, without a doubt, saved her life—was given the honor of presenting her with this notable proclamation.

Alice approaches life with an attitude of not giving up more than she has to. With that goal in mind, she participates in clinical trials, exercises regularly, maintains a nutritious diet and relies on her steadfast determination to ensure that she spends her time living well.

As for what lies ahead, Alice plans to enjoy many more years advocating for COPD and Alpha-1 and spending time with family, friends and colleagues.

pursue her larger goal of advocating for COPD and Alpha-1 awareness.

Alice is a firm believer in sharing her experiences and providing information

A Community of Service

Managing patient case loads while working full time from home can require the focus and discipline of a military veteran. Several of AlphaNet's employees have enriched the Alpha community with their discipline, creativity and strong work ethic — qualities that were acquired and developed while serving in the United States Armed Services. We owe all veterans a debt of gratitude for their service to our great country and, with that in mind, AlphaNet is pleased to recognize our veteran colleagues.



Richard Sanchez, AlphaNet's most recent post-military hire, was born and raised in Miami. He served as a Configuration Management Technician with the U.S. Air Force from August 2001 to June 2005 and spent three of those years stationed in Alaska. Richard received a B.S. in Information Technology from Florida State University in August 2009. He joined the AlphaNet team in June 2010 as an IT Support Specialist and has proven himself an invaluable asset to AlphaNet, the Alpha-1 Foundation, the COPD Foundation and the Alpha-1 Association. "Richard came out of the Air Force with not only an impressive skill set, but also an impeccable work ethic and sense of discipline," Edward Parker, AlphaNet's IT Manager, said. "He is comfortable with assisting end-users of all skill levels and is tremendous at multi-tasking and prioritizing."

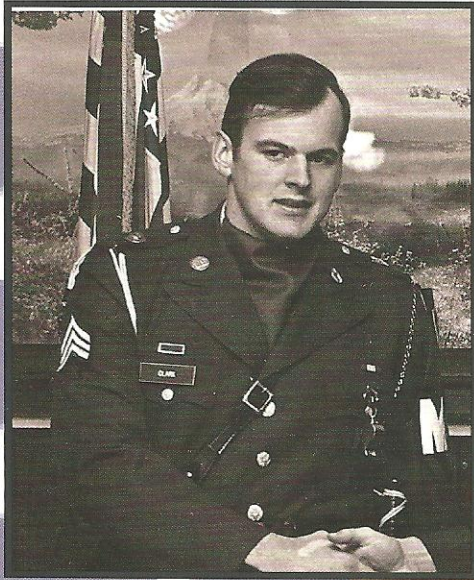
When asked if her military experience has helped her in her current work for AlphaNet, Coordinator Jean McCathern answered with a resounding, "Yes!" Jean regularly relies on her extensive background in communications and her organizational skills to assist her Alphas.

Jean managed more than 200 technical personnel and an annual budget in excess of \$3 million for the U.S. Air Force. The skills she acquired during her time in the Air Force certainly come into play when working with patient case management. Additionally, her years of military self-discipline have helped her stay focused when working from home where the temptation for distraction is sometimes overwhelming.

Jean served for 25 years, ending her military career as the Superintendent of the 789th Communications Squadron at Andrews Air Force Base, MD. Jean holds a B.S. in Industrial Technology from Southern Illinois University— Carbondale, and is pursuing post-graduate work in Public Administration at the University of Management and Technology in Arlington, VA.

Jean is a former Alpha-1 Association support group leader. She currently serves Alphas as a coordinator from her home in Pennsylvania.





Dan Clark served our country as a Sergeant in the U.S. Army Military Police and was stationed at Stewart Air Force Base while working at West Point in New York. Dan credits the Army for his eventual life choices. In speaking about his time in the Army, he states that it “provided my path to my law enforcement career, and law enforcement led to my AlphaNet career.”

In the 1970s, while serving as an Army police patrol officer who was promoted to a Training Sergeant for the Military Police Company (including leading several civilian and military police officer training programs at West Point), Dan applied and was accepted into the Army's officer candidate school. Fate would play an important role in Dan's life as one of his lungs collapsed just months prior to the beginning of what he thought would be his next adventure with the military. Dan received the medical help he required and, while in recovery, he re-applied for officer candidate school. Dan was again accepted into the school but his second

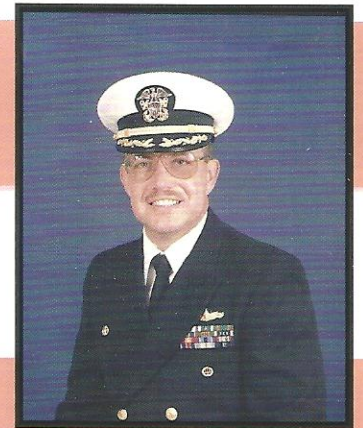
lung collapsed forcing him to pass, yet again, on officer candidate school and to be put on a three year waiting list for that training. Dan decided to leave his career with the Army in pursuit of civilian law enforcement.

Dan achieved a bachelor's degree in Police Administration and Corrections from Mercy College of Detroit and a master's degree in Criminal Justice from the University of Detroit. Dan also served his community of Troy, MI as a 25-year police officer with the City of Troy Police Department. In addition, Dan continues his legacy of civic duty by serving his Alpha community as a coordinator for Michigan.

As with many Alphas, Mike Benn's symptoms started later in life at the age of 57 when he began experiencing chronic bronchitis. Mike was initially treated for asthma unsuccessfully and was then sent to an allergist who confirmed that Mike did not suffer from allergies. It was this allergist and former military physician, however, who decided to run a battery of tests on Mike, which led to an eventual Alpha-1 diagnosis. Mike is thankful for his speedy diagnosis (18 months from the beginning of his symptoms to his diagnosis), noting that many people suffer for years before finding out that they have Alpha-1.

Mike joins Richard, Jean and Dan as a veteran-turned-AlphaNet employee. Mike served for 26 years in the United States Navy, retiring at the age of 46 as the Assistant Chief of Staff Operations/Kaho'olawe Project Officer stationed in Pearl Harbor, HI. In addition to Mike's extensive naval education and rank as Naval Officer for the majority of his military career, Mike holds a B.A. in History from Warren Wilson College.

Mike is thankful to have found AlphaNet and his current position as a coordinator. He had been working as a financial advisor in a position that required a great deal of footwork. His diagnosis, combined with the physical exertion that was required of him at his job, forced him to retire in September 2009. Six months later, Mike saw an ad in *The AlphaNetter* for a coordinator position. Mike applied, received the position and, since then, has been enriching the Alpha community with his discipline, insight and work ethic.

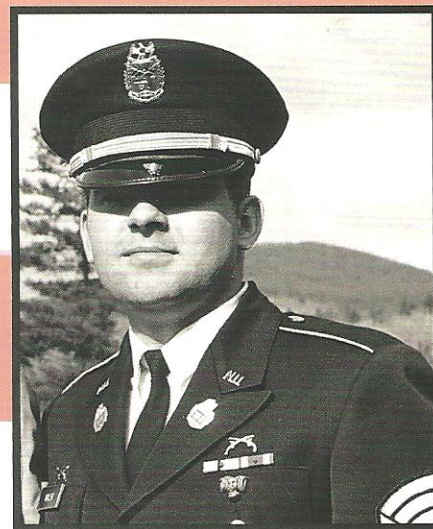


John Walsh's military service began at Norwich University where he was a member of the ROTC while attending this prestigious military college. John spent much of his military duty time in special active training and as a member of the 11th Special Forces Group, USAR. His Airborne and Ranger training taught him the self-discipline and self-confidence to overcome obstacles and the realization that he could accomplish anything he set his mind to. In speaking about his time in the 11th Special Forces Group, John points out that he acquired invaluable skills that he would take with him to his future civilian careers. "My military experience provided me with the necessary skills to deal with situations where only limited resources were available to get the job accomplished," John said.

While still serving as a reservist in the Special Forces, John worked as an ombudsman for former U.S. Senator Peter H. Dominick. From there, he was recruited into a Special Operations Group and assigned to the Kingdom of Saudi Arabia where he worked for eight years. While working in intelligence, John again learned vital skills which would prove to be quite helpful in his future role as a leader. "My background helped me develop skills to learn how to assess alternative pathways to problem-solving and make the necessary judgments to move forward," John said.

After returning from Saudi Arabia, John transitioned quickly into pursuing an interest in marketing technology and created an integrated controls business in Washington, DC, Maryland and Virginia. In 1989, while working as CEO of his controls systems company, John and his brother Fred were diagnosed with Alpha-1. John soon discovered that little was known about the condition and even less research was being conducted to find a cure. Knowing that, John and fellow Alphas Susan Stanley and Sandy Lindsey joined forces to form the Alpha-1 Foundation in January 1995. John then went on to co-found AlphaNet later that year.

John's civic service has extended well beyond the walls of the Alpha-1 Foundation and AlphaNet. He has served on numerous health agency committees and government advisory committees and has served as chairman of the National Health Council, co-founder of the Plasma Users Coalition, and trustee of the Foundation of the American Thoracic Society, to name a few. John currently serves on the NIH Director's Council of Public Representatives and Council of Councils.



CLINICAL COLUMN

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

Now that spring has fully arrived and summer is fast approaching, be aware that with the warmer air and the blooming flowers comes its own set of precautions for Alphas. It's a time when the birds and bees are busy pollinating and you may be busy spring cleaning or planting a garden. While these activities are fun and healthy, breathing the outdoor or indoor pollution associated with them may trigger shortness of breath or lead to a lung infection. Try to avoid strong chemicals, aerosol sprays and other indoor pollutants such as chimney smoke. Avoid inhaling fumes from chemicals or fertilizers used in gardening and avoid being outdoors during any pollution alert. You can check out the Weather Channel (www.weatherchannel.com) for air quality and pollen forecasts. If pollen or pollution is high, postpone your outdoor activities. Be cautious, stay healthy and go ahead and plant a healing garden, fill those bird feeders or, even better, just get outside and enjoy the lovely weather!

Alpha Takes Steps to Improve Health

On any given day, chances are good that you will find Alpha Mike Pendergast taking his routine 5 to 7 mile walk along the rolling hills and mountains of his western North Carolina town. Despite his intense dedication to exercising and staying active, Mike, in reality, wasn't always such an avid walker. In fact, less than two years ago Mike was on an active transplant list awaiting new lungs and could only dream of walking more than five miles without the help of oxygen.

What transformed Mike's whole outlook on exercise and what led to his remarkable improvement in lung function started with his participation in AlphaNet's Step Forward Study, a five year-long clinical trial which began in September 2009 that tracks the effects of diet and exercise on the health of Alphas. Shortly after the onset of the study, Mike was put on the lung transplant list. In February 2010, he started a regular exercise routine, walking about two miles in 50-55 minutes with oxygen. Mike admits that what inspired him to start walking was simply the motivation he felt from being a participant in the study and the encouragement he received from his coordinator Gayle Allison Tipper. "I don't know how long I would've kept up with a consistent exercise plan if it hadn't been for the study. I walked because I had a goal to accomplish and because I saw results." For Mike, these positive results became quite noticeable within mere months of starting his regimen. By May 2010, Mike was able to walk five miles a day in an hour and a half without oxygen.

With his improved lung function Mike suddenly found that he could once again accomplish certain simple tasks which only months prior had been a struggle. "I was able to go up and down the steps in the front of my house without a lot of exertion and I could carry groceries and the laundry much more easily." One of the most significant changes that Mike noticed was his increased ability to keep up with his grandchildren. "I could go out and participate in a lot more active things with my grandchildren," Mike said.

As Mike continued to walk regularly, he successfully lost 15 pounds and was walking up to seven miles a day by early summer. After just four months of consistent exercise, Mike had experienced such a notable change in his lung function that in June 2010 his transplant doctors told him that he was too healthy to receive a lung transplant and that his quality of life, along with his health, made taking the chance with a transplant unwise at the time. He was, therefore, taken off the active transplant list.

As of now, Mike continues his 5 to 7 mile walks every day—barring rain or snow!—and remains off the active transplant list. Much of Mike's persistent dedication to staying active is certainly derived from the impressive positive changes that he saw in his health as a result of his walking. He points out that "feeling good and my improved quality of life have become my main motivators to continue. I am amazed by how much better I feel!" With this, it seems evident that Mike won't soon be abandoning his daily walk.

Are You Traveling This Summer?

Here are a few things to remember when traveling this summer with Alpha-1:

- Discuss your travel plans with your physician. Have the physician write a letter explaining your present condition with a list of current medications and/or oxygen needs.
- Obtain a written prescription for your oxygen, including the flow rate.
- Have a few extra days of all routine medications and make sure to pack them in your carry-on bag.
- Keep your travel documents readily accessible: plane tickets, boarding passes, passport, ID, medical information, emergency cash, credit cards and medical insurance cards.
- When booking your flight, consult with the airline about their policy regarding on-board use of oxygen.
- Try to avoid illness while traveling. Wash your hands frequently and pack antibacterial wipes/spray.
- If you are planning an extended stay and will need your augmentation therapy, make arrangements with a home care company.

For more information about traveling, please consult the Big Fat Reference Guide at www.alphanet.org.

Alpha-1 Association Education Days

co-sponsored by the Alpha-1 Foundation

August 6
Portland, OR

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.

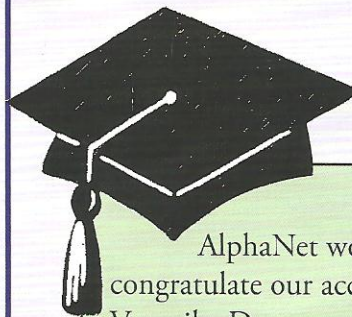
Alpha-1 Foundation Event Calendar

July 16 - "Get the Scoop on Alpha-1"
Des Moines, IA

August 13 - Leadville Trail 100 Mile Bike
Race
Orem, UT

September 30 - Team Alpha-1 Escape to
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.



AlphaNet would like to congratulate our accountant, Veronika Dosseva, on her graduation. She received her master's degree in Accounting from Florida International University on December 13, 2010. Veronika pursued an accelerated graduate program that allowed her to complete her degree in ten months. Veronika's hard work and commitment to her profession are commendable. Congratulations!

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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