



SUMMER
2008

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The AlphaNetter

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AN ALPHA CELEBRITY

She's been featured in the *National Enquirer*, *People*, *USA Today*, *Newsweek*, *Modern Bride*, *Business Week* and on the Paul Harvey radio show, *Voice of America* as well as Yahoo! and AOL... an Alpha-celebrity, Linda Katz.

How Linda found this notoriety is a mixture of her creativity, sense of fun and

a dash of good luck. Four years after her Alpha-1 diagnosis, in 1994, Linda was the seventh person in her Southwest Kansas town of Garden City to get internet access. She wanted to learn how to make web pages, so she began to put together an experimental site. She gathered all her nieces and nephews, borrowed some tools and heavy equipment from her family and friends and set about photographing the workers (aka the "executives") from the *"Prairie Tumbleweed Farm"*

www.prairietumbleweedfarm.com.

Linda had a lot of fun writing copy for the Farm and dubbing Garden City "the tumbleweed capital of the world." She wrote, tongue-in-cheek, about her "quality tested" tumbleweeds and offered suggestions for a variety of uses including as Christmas trees, home décor, landscaping, and for proms and dances.

Much to her surprise, her practice posting on a search engine started generating actual orders. Today, she runs a thriving business selling three sizes of tumbleweed, all with the guarantee "if they don't tumble, we don't sell them." Her husband, son and grandchildren all help when needed.

Buyers are diverse and some are also very well known. Many purchases are for use in movies, TV shows and commercials such as *Barney: The Purple Dinosaur*, and the movie *Finding Neverland*. Others are for commercial décor such as in the stores of Pottery Barn and Ralph Lauren. They have been in the U.S. Capitol and even NASA has bought from the Farm, for use when testing the Mars Tumbleweed Rover (which is shaped like a beach ball).

After watching her Dad die from Alpha-1, Linda takes care of herself and today feels good. She has participated in Alpha-1 studies and enjoys looking into her genealogy, that is, when she's not tending the Farm.



Linda Katz (right) gathering tumbleweeds with her two nephews Jarred Waller (left) Jacob Waller (center).

New Recommendations for Disposal of Infusion Supplies

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

In April, a letter from AlphaNet, “Recommended Medical Waste Disposal Procedure Update,” was included with each infusion supply order mailed to you. This letter provided updated information regarding the disposal of certain types of infusion supplies commonly known as “medical waste.”

Because this important information will directly change how you and/or your infusion nurse dispose of your infusion supplies, we felt it was important to include the letter here in the event that you didn’t receive it or did not read it. Also, please be sure to pass on this letter to your infusion nurse as they may not know about these important changes in procedure.

If you or your infusion nurse has any questions or concerns about these new recommendations, please don’t hesitate to contact me. I can be reached at 888-553-0093 or at tkitchen@alphanet.org. And, as always don’t hesitate to contact your AlphaNet Patient Services Coordinator directly with any questions.

RE: Recommended Medical Waste Disposal Procedures Update

In the past, disposal procedures for empty Prolastin® medication vials, used IV tubing and IV bags have required the use of a biohazard container, also referred to as a “sharps container.” This practice has been followed for many years. Today those precautions are no longer necessary.

Pharmaceutical companies have revised their manufacturing processes and have incorporated new procedures to deactivate possible viruses or other microbiological contaminants that may be present in donated human plasma. These measures have been extremely successful in addressing the overall safety of biological products.

In March, we contacted both the Centers for Disease Control (CDC) and the Environmental Protection Agency’s (EPA) Region 7 office. We asked them if they had developed any specific guidelines related to the disposal of medications that are manufactured from donated human plasma and the products used to administer these drugs. They did not have any specific guidelines or recommendations on the disposal of these products. Their position is that these products would not be considered infectious since they have been processed and manufactured in compliance with pharmaceutical standards.

In addition, it is our understanding that many pharmacies and hospitals dispose of these products in their normal trash and not with biohazard products.

The only exception to this information is if your IV tubing had visible blood back-up, at any time during the infusion, then it should be considered biohazardous and discarded in the “sharps container.”

Given our current information and guidance from the CDC and EPA, it is our recommendation that Prolastin vials, and the equipment used to pool and infuse Prolastin, do not require any special handling for disposal and can be discarded safely with your normal household trash. Of course, you should continue to dispose of needles, and other hazardous materials in the biohazard container.

For more information, please call your AlphaNet Patient Services Coordinator.

*Sandy Sandhaus, MD, PhD,
Medical Director, AlphaNet*

*Terry Young,
General Manager, AlphaNet*

New York City Alphas Meet

Twenty-nine Alphas and guests gathered this past Spring and enjoyed a luncheon meeting at New York’s Blue Fin restaurant. Participants welcomed newly diagnosed Alphas as well as listened to presentations by Donovan Quill, about Alpha-1 and his family, and Pat MacInnes, who discussed the need for a cure. As a special bonus, the meeting netted \$200 for the Alpha-1 Foundation.



Peter Duttweiler is a man on a mission. Credited by many as the unstoppable force behind Veteran's benefits for those with Alpha-1, Pete worked diligently and methodically for years to obtain medical rights from the Department of Veterans Affairs (VA).

It wasn't until his Alpha-1 diagnosis in 1990, that Pete began to understand why his health had been so poor. The more he researched about Alpha-1, the more he found out about lifestyle and environmental factors and their impact on the disease. He immediately recognized that his service record, including a year in Vietnam, had put him in the most detrimental of circumstances to rapidly accelerate his disease progression.

ALPHA VETERAN KEEPS SERVING OTHERS



On the (Internet) Road Again Some of you out there might recognize Pete by his on-line handle of "PeterD." He has been posting articles about Alpha-1, Veterans, and lung issues on various e-mail lists for the last 10 years.

But Pete is a man of action – so he began to work on many fronts. By 1994, he was participating in a support group, started by Alice Dunkley, in Central New York that attracted about 10 people each month. He was inspired to put together an anthology called the "The Alpha Atlas" featuring 100 Alphas from around the world and their stories of coping with the disease. Through distribution at an early national conference and posting on-line, the stories were among the first about Alphas and very well received. Edited with the help of his wife Eileen, the collection became a catalyst for bringing Alphas together and sharing information.

Pete was finally forced into retirement from the U.S. Postal Service in '92 when his lung capacity and function continued to decline.

Throughout the years he was also fighting another battle – this one with the U.S. government to get the medical benefits he felt he, and other veterans, deserved. He meticulously documented his own medical case history. Carefully researching details such as the location of "Agent Orange" spraying during the Vietnam War, he tracked down and pulled together other Vets to document their medical information. He collected photographs, researched weather data, worked with AlphaNet Medical Director Robert A. Sandhaus, MD, PhD, and made a connection with a sympathetic, very helpful officer from the

Disabled American Veterans Association. The process took five and a half years.

The year following his retirement, after serving in conditions that dramatically compromised his health and suffering through more than 20 years of misdiagnosis in the VA medical system, Peter finally had both a correct diagnosis and benefits to help him get life-sustaining treatment.

But Pete's mission is not finished. He still works daily to help other Vets and to interact with other Alphas from around the U.S. To date, he has helped approximately 70 Veterans receive some level of benefits. There are still unresolved issues with certain aspects of Pete's VA benefits, specifically regarding asthma and nicotine addiction, and he has taken that battle through the VA system where it is now under review and awaiting a decision from the Board of Veterans Appeals.

He has helped many Vets over the years. In the words of one Virginia-based Alpha-Vet, "Pete's a college grad and able to put things into place; he really came through and helped a lot."

"Pete was really the first one to fight for Veteran's benefits for Alphas and he's still pretty much the main guy to go to," said Texas Alpha Dave Courtney. "Peter helped me a lot with advice and samples of documents and I have consequently helped some other folks."

For more information about obtaining Veteran's benefits, contact your AlphaNet Patient Services Coordinator.

Department of Veterans Affairs:

www.va.gov

"I have Alpha-1; Alpha-1 does not have me."

A life-long love of exercise and healthy living are now paying off big time for Alpha Jim Trimble. His mantra "I have Alpha-1; Alpha-1 does not have me," offers daily inspiration to this California resident who loves the outdoors.

Jim recently completed the 25-mile Tour de Palm Springs charity bike ride for Team Alpha. But a 25-mile ride is a piece of cake for this avid biker, who rides by himself three to four times a week, usually 25 miles a shot.

A retired grocery store owner, Jim and his wife have four grown children and split their times between homes in Piedmont (San Francisco Bay area) and Palm Springs. He began cycling close to 40 years ago after an injury in the Marine Corps stopped his routine running.

Jim and his wife are vegetarians and big proponents of healthy nutrition. There is no doubt his life-long good habits



helped him stave off the impact of Alpha-1, but eventually Jim was still becoming short of breath. About a year ago, he sought out the cause and gained an almost immediate diagnosis of Alpha-1.

At six feet tall, Jim's body was struggling. Following his doctor's advice, he began using oxygen, taking a 10-pound liquid portable oxygen container along on his rides. He's resting

better, eating more and has been able to gain an additional 10 pounds because he is not burning as many calories trying to breathe. His lung capacity has improved in the last year to 47%.

On his off-days he swims, practices fly-fishing and pursues his passion of reading.

"I'm going to make the most of my life, the more I can exercise the healthier I will stay," explains Jim.

Jim plans to keep riding – for Alpha-1 and himself.

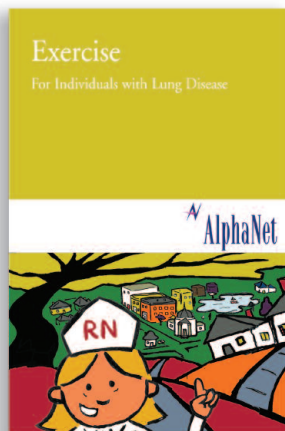
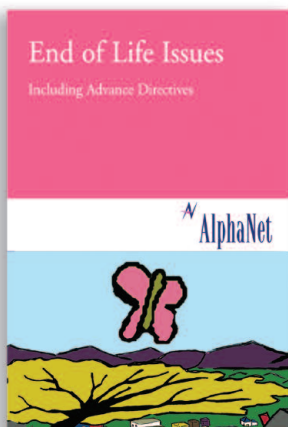
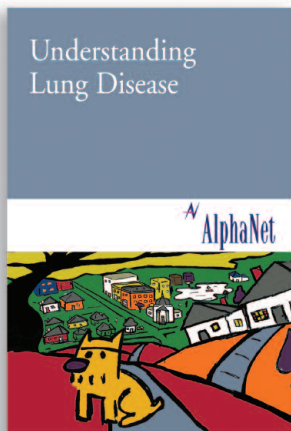
HOT OFF THE PRESSES!

NEW SPECIAL TOPIC REFERENCE GUIDES AVAILABLE

Three new special topic brochures have been added to the AlphaNet library and are now available: *Exercise For Individuals With Lung Disease*, *Understanding Lung Disease* and *End of Life Issues, Including Advance Directives*.

Previously existing topics are also still available and include: *Traveling with Alpha-1*, *Oxygen Therapy*, *Understanding Pulmonary Exacerbations*, *Staying Healthy: Management of Environmental Risk Factors*, *Medications for Alpha-1 Lung Disease*, *Augmentation Therapy* and *Understanding Pulmonary Function Testing*.

The guides offer focused information on single topics and have both included and expanded on the material in the *Big Fat Reference Guide*[™]. For copies, call AlphaNet at 1-800-577-2638 and ask for extension 243.



Planning for Air Travel Just Got Easier

New federal legislation now requires all airlines to allow passengers needing portable oxygen to utilize personally owned POCs (portable oxygen concentrators). The U.S. Department of Transportation (DOT) announced the new legislation this May, which applies to domestic airlines and all foreign carriers leaving or arriving in the United States.

This does not eliminate the need to coordinate travel plans, in advance, with each airline, since specific guidelines do vary with each carrier. Additionally, the Airline Oxygen Council of America (AOCA) now has up-to-date, comprehensive information and guidelines about traveling on airplanes with oxygen.

For information, visit: www.airlineoxygenCouncil.org

Then click on “Take Action!” tab at top and look for heading “Airlines and Their Criteria for POC Usage.” Once on the list, you can click on a specific airline for more comprehensive information.

*THE AOCA HAS ESTABLISHED THE FOLLOWING GOALS:

1. Make travel with supplemental oxygen an individual’s right - with enforceability;
2. Allow oxygen needs to be successfully met during air travel as well as in all phases of life;
3. Establish a strategy to promote access to current and new technology to be allowed as carry-on, and;
4. Have oxygen accessible, consistently delivered, and implemented under the same guidelines by all air carriers.

*There are currently five portable oxygen concentrators (POCs) that have passed DOT and Federal Aviation Administration standards and are voluntarily allowed as carryon items which can be operated aboard aircraft:

Use some sort of cute bullets instead of the numbers and change to:

- Freestyle by Airsep
- Eclipse by Sequal
- Evergo by Respirationics
- Inogen One by Inogen Co.
- Lifestyle by Airsep

**Information from the AOCA*



All of a sudden I got a nasty crick in my neck...

Since Jim “Bones” Carbone was a kid and used to caddy for his Dad, he has loved the game of golf.

Jim says he knows a lot of people who say they aren’t well enough to play, but he feels golf is one of those “moral imperatives” (like eating a hot dog at a baseball game), that just has to be enjoyed. His game may not be what it used to be and when you ask him his golf handicap, he quickly responds “my swing,” but he still plays courses near his Cincinnati home an average of once a week.

Jim retired from a career as a medical sales rep and surgical assistant and had to give up his hobby of playing and singing in local bands, but even a lung capacity of 35% will not keep him off the golf course. He credits his 27-year-old son, Jason, with getting him back on the course and helping him with his “incredible ingenuity, patience and love.”

Another side of Bones is that he is also a bit of a comedian and has re-created a series of oxygen-related mishaps as photo-cartoons. *Pictured above: his oxygen line gets tangled around the tee marker.*

The course is the Nicklaus-designed Kings Island.



Alpha-1 Foundation & Team Alpha

Summer 2008

Swim the English Channel
New York, NY

June 27-29

Breathe Easy Bike Ride
Santa Barbara County's Wine Country
Santa Inez, CA

July 11-16

U.S. Transplant Games
Pittsburg, PA

July 26

Plymouth Harbor Watch Cruise
Massachusetts

August 24

Accenture Chicago Triathlon
Chicago, IL

August 31

Disney Half Marathon
Anaheim, CA

September 12-14

24th "Escape to the Cape" Bike Trek
Plymouth to Provincetown, MA

September 14

Maui Half Marathon
Maui, Hawaii

October 6

Lone Star Alphas Shoot for a Cure 3rd Annual
Golf Tournament
Flower Mound, TX

October 20

Santa Clarita Half Marathon
Valencia, CA

To find out more about these or other events in your area, log on to www.alphaone.org or call toll-free: 1-888-825-7421, ext. 248.

Alpha-1 Association Programs & Activities

July 12

Dakotaland Support Group Meeting
Sioux Falls, ND

August 16

Regional Support Group Meeting
Lebanon, NH

September 20

Alpha-1 Education Day
Chapel Hill, NC

September 27

Regional Support Group Meeting
Las Vegas, NV

October 4

Alpha-1 Education Day
Boise, ID

October 18

Alpha-1 Education Day
Pittsburgh, PA

To find out more about conferences and support groups, visit the Alpha-1 Association website at www.alpha1.org or call toll-free: 1-800-521-3025



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**YOUR SUMMER
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