



SUMMER
2008

The AlphaNetter

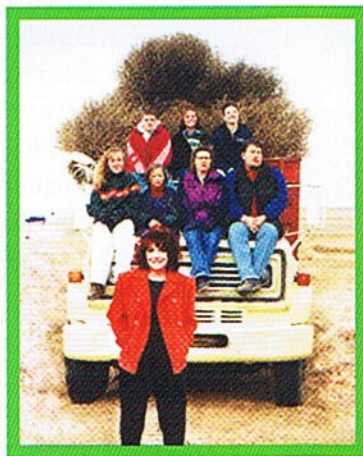
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AN ALPHA CELEBRITY

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.

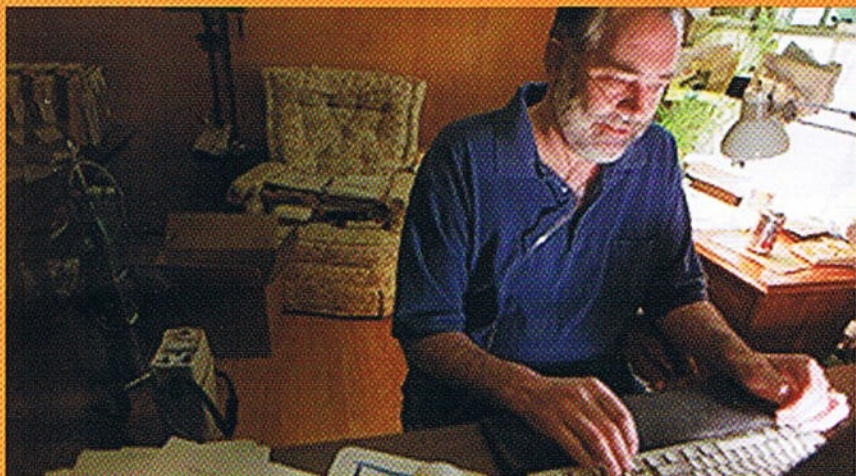


Linda Katz (right) gathering tumbleweeds with her two nephews Jarred Waller (left) Jacob Waller (center).

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.

