

The AlphaNetter is a quarterly publication of AlphaNet, Inc.

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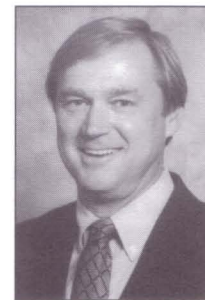
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THE

AlphaNetter

Message from Your New CEO

— by Bob Barrett



Robert C. Barrett

I couldn't quite grasp the concept when I first heard about AlphaNet. A not-for-profit corporation... founded by three individuals afflicted with alpha₁-antitrypsin deficiency, a little known and widely misunderstood lung and liver disorder... a business that employs Alphas who coordinate the insurance benefits, pharmacy, infusion and ancillary healthcare services of other Alphas nationwide... a compassionate company which supports Alpha community programs and returns its profits to support research for improved treatments and a possible cure for the disease. Run that by me again... .

Unique, I thought. Creative. Logical. I felt I might have an opportunity to play a meaningful role in moving this company forward. In May 1998, after a lengthy interview process, I was hired by AlphaNet. Since then, I have been learning about the company and its resources, the disorder and its effects on Alphas and their families, the therapies and the possibilities. I have concentrated my efforts on insuring a solid financial footing for your organization.

I consider it is a privilege to work for you. I will do my best to position AlphaNet to provide the widest range of meaningful, high quality, cost-effective services possible to our members. I believe that AlphaNet has the expertise to be the preeminent, not-for-profit, disease-specific, integrated health delivery network in the United States.

This quarterly newsletter is a communications vehicle written for, and by, AlphaNet members and staff. Please use it. If you have a question which you would like addressed regarding AlphaNet services, Prolastin, or any other area related to alpha₁-antitrypsin deficiency, please send or e-mail it to your coordinator or me. We'll get you the answer. Or, if you have an interesting article or story that you would like included in a future issue of AlphaNetter, send it. Space permitting, we'll print it. We also welcome your comments, suggestions and criticisms.

Best wishes to you and your families for a happy and healthy 1999!

AlphaNet Milestones

AlphaNet is a not-for-profit corporation created in 1995 with the twofold mission of improving the health and well-being of its AlphaNet patient members and contributing toward alpha₁-antitrypsin deficiency research activities. Its unique corporate structure supports an integrated disease-specific health management model for the Alphas it serves, while advancing knowledge of the disease that affects them.

Managing alpha₁-antitrypsin deficiency is complicated and involves dramatic life-style changes for those suffering from the disease. AlphaNet encourages a holistic approach to healthcare, consolidating therapeutic services, social services and reimbursement counseling. AlphaNet coordinators, who are Alphas themselves, help patients plan their care and work closely with the caregivers to provide effective, cost efficient augmentation therapy and other health services.

In addition to producing a more balanced and consistent state of health, AlphaNet provides significant cost savings to its subscribers. The cost of augmentation therapy has been reduced by as much as 30% during AlphaNet's three years of operation.

AlphaNet returns all net revenues to support research efforts of the Alpha One Foundation and other programs of the Alpha community. During the fiscal year ended June 30, 1998, AlphaNet donated over \$100,000 to the Alpha One Foundation, funding Phase One of a Cost of Illness Impact Study, one of the first initiatives of the Alpha One Registry, as well as other research and programs.

During the recent Prolastin® shortage, AlphaNet distributed Health Tips for Alphas, a pamphlet to help Alphas deal with the crisis, and coordinators assisted members and nonmembers alike

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in their attempts to secure Prolastin, an intravenous augmentation therapy. AlphaNet is currently funding the development of a comprehensive Disease Management Program specific to alpha₁-antitrypsin deficiency.

Additionally, AlphaNet funded the following programs and projects for the Alpha community:

- ◆ All Regional and Alpha₁ National Educational Conferences,
- ◆ The 1997 Alpha₁ National Association Florida Chapter Christmas Card, featuring artwork by Bill Reese,
- ◆ The annual Alpha₁ National Association golf tournament,
- ◆ The Alpha₁ National Association's pulmonary function testing educational brochure undertaken in association with the American Association for Respiratory Care,
- ◆ The study on marital coping by Chris Cannon, Ph.D. at the University of Delaware.

These programs and contributions would not be possible without the dedication and determination of the coordinators. They are truly "Alphas Serving Alphas."

The Nurses' Station

— by Janis Berend, R.N.

I have been working with Alpha patients for 9 years. Prior to coming with AlphaNet 3 years ago, I was a coordinator for the NIH Registry Study and am currently the coordinator of the Alpha₁ Clinic at National Jewish Medical and Research Center in Denver, Colorado working with Dr. Robert Sandhaus. I have a Masters degree in Nursing and am a Certified Nurse Practitioner. I am also a diabetic and have had a kidney transplant; I am currently on the list to receive a kidney/pancreas transplant. I know what it is like to have a chronic disease.

I want to work with AlphaNetters to be sure that you are comfortable with your nurses and also, to help your nurses with any questions they might have regarding infusion or patient care. I look forward to working with nurses and patients in establishing plans for care and am willing to communicate with patients, nurses, doctors, insurance companies, employers, etc., — anyone who might need or want my assistance.

We are currently writing a Disease Management Program that will provide us with outcome information about the best care options for patients with A1AD so

that both Alphas and their nurses will know how to address the problems that may arise — and better yet, prevent some problems from arising.

Working together, we can make things easier and safer for everyone. Please don't hesitate to call me. I love my job, and alpha₁-antitrypsin deficiency is my favorite subject.

Janis Berend is the Director of Nursing for AlphaNet. She can be reached at:

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Product Reviews

• **SCANDISHAKE®** is a calorie dense product in powder form that, when mixed with whole milk, supplements your diet to help keep or put weight on.

• **The FLUTTER®** is a small, handheld, mucous clearing device that provides positive expiratory pressure (PEP) therapy which can benefit COPD patients.

Both products are available through Scandipharm®. For more information call 800-950-8085 or check out the website at <http://www.scandipharm.com>.

Coordinators' Corner

Computer Experience

— by Joyce Finch

When I was diagnosed with alpha₁-antitrypsin deficiency in January 1992, I had never heard of this disease and, since I did not have access to a computer, could not research it on the Internet. I was given two names of others in the State of Michigan who also had A1AD; one was Mary Pierce who resided in St. Joseph, near the Indiana border. We spoke quite often and, after her double lung transplant, we were able to meet for dinner. Mary's post-op stay in Grand Rapids, a much larger town than either of us lived in, gave her and her husband, Todd, the opportunity of shopping in large computer stores.

I was very curious about computers and wished I had one. One day, our son, John, sent us an Apple computer that he was no longer able to use. I quickly discovered that I knew absolutely nothing about

computers, let alone "surfing the web!" I remember calling John in California for help in solving all my computer dilemmas; he became my exclusive technical support person.

One day, I decided to just play around with the computer without being connected on-line. I went to the file menu, clicked on all options, and had a great time learning all the wonderful options available to me. Then I heard about chat rooms, searching, downloading, etc. and my vocabulary took on a whole new world of words! My family was impressed with my knowledge and I became braver about looking things up on the Net.

I attended the National Conference in Minnesota and met many other Alphas whom I had only "spoken to" via e-mail. It was such fun to put faces with names and to actually meet friends from all over the USA and the world.

My experience with the computer has given me a long list of "bookmarks" which consists of favorite web pages that I like to visit on a regular basis. Those

sites are the Alpha One Foundation, AlphaNet, the National Alpha₁ site and Alphaslink page. I also can look up any prescription or medication at <http://www.rxlist.com>. Or, I can find the latest medical information at Medscape (which also shows the lungs of a person with A1AD)! At CNN and Reuters news I can receive instant health news regarding the latest information about transplants, allergies, Cystic Fibrosis, COPD, etc.

I have found the possibilities for information hold no boundary. I hope you have access to a computer and are able to open a whole new world for yourself. If I can be of any help or answer any questions, please let me know.

Joyce is the Midwest States Regional Coordinator for AlphaNet. She resides in Michigan with her husband, Ed; her three adult children reside in the same town. She can be reached at:

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PROFILE: An Objective Look at Courage

— by Viki Reed

My sentiments and biased point of view would love to prattle on, telling everyone about my best friend, Julie Bakula. I could share the details of how Julie raised two children, pretty much on her own, and how she survived two marriages that resulted in the deaths of her spouses. But Julie is a private woman and I respect that.

I could tell you how much her friendship has enriched my own life; maybe I have even become a better person for knowing her. She freaked me out the first time I met her, the first time a group of Alphas ever came together in the State of Maine. Directly across the table from me sat this woman on oxygen. She shared her story of how, just months before, she had visited her doctor on her lunch hour from work for a bad case of bronchitis. She walked out of that office with an oxygen tank; it was the point of no return for her on this wild ride we call Alpha. For me, it was like looking into a mirror at my own future and I didn't like it one bit.

I could go on for hours about our crazy trip down to the Cape Cod Trek back in 1996. It was unforgettable, the people we mingled with, the laughter, the frustration, the angry moments, the love, the tears... There were times during the last leg of the journey that Julie and I couldn't decide whether we loved or hated each other. That is only fair after spending three days cooped up in the cab of a pickup truck together! One thing that we concluded after that trip; both of us have a lead foot and have a knack for looking like we know exactly where we're going, when in reality, we're hopelessly lost.

But what comes to mind in trying to describe Julie to those who aren't as blessed as I am from personally knowing her, is last year's icestorm. In addition to the qualities that I've used to describe her, in all fairness I have to say that Julie is stubborn and bullheaded to the point of being infuriating to me at times. Not only to me, but to our support group, her nurse, her doctors... And her response to last year's icestorm was a perfect example of this.

We were hit with the worst ice storm in recorded history up here and Julie had no electricity at her house for nine (or

eleven) days. Now mind you, not that this is an insult, but Julie is "from away" and not totally accustomed to the harsh physical elements that go along with living in Maine — especially when the electricity goes out, which it often does during the winter. The only thing she had in her house was a very small inefficient wood stove in the living room, that needed to be stoked every four hours or so to keep from going out. No running water, no TV or radio, no coffee!!! She determined that she was staying home, despite the fact that many of us lived in an area which still had electricity. She was staying home with her dog and intended to keep that fire stoked so her pipes wouldn't freeze and that was all there was to it. I think I forgot to mention that she was awaiting transplant at that time and had no one living with her to help out in the day to day living routines.

As you can well imagine, she had our local community in an uproar. Even Steve's (my better half's) threat of driving to her house and physically removing her from her home wouldn't budge her. He's a strapping guy but that didn't compare to her determination. Happily, I can say that Julie made it through this ordeal and she accomplished her goal, but that is not my main point of sharing this story.

During the icestorm the difficulties that it presented in many lives were obvious, the whole nation got a look at it on the world news for days. But it was after the storm, while driving around, that the devastation really became obvious to me. For miles, acres upon acres, of the trees in our forests were broken. Huge trees, hundreds of years old, snapped right in half, or at the very least their tops broke off. It broke my heart and I found myself wondering, "Will my world ever look right again, be healthy again?"

There is one tree that is unique to our northern forests, the white birch. Everyone knows it for its beautiful bark, but its truly unique quality is in its flexibility. The white birch doesn't break, it bends. Among the broken maple, oak, pine and beechwood trees is the white birch, small and large, some of them bent right to the ground, but not broken.

This spring brought a new flush of green that covered up a lot of the brokenness and we could forget about the storm for awhile. The white birches straightened up a little bit over the summer and it got so that we hardly noticed anything had happened. Now that the leaves are gone, we're once again reminded of that ice storm. But the white birches are still



alive, and the rest of the forest is renewing itself as well. I look forward to springtime, when the birds return and my world is green, and I suspect that the white birches will be just a little straighter.

Julie had her transplant on October 3; it has not been an easy road for her. I can only imagine the depths of her frustration on wanting to be healthy and free from that hospital. She has been through hell and back and there's not much more that we can do but give her call once in awhile and let her know that we love her.

In my heart, Julie is like that birch tree; I have confidence in her inner qualities and strength — things that are impossible to measure, but I think it's all in the sap.

Viki Reed is an AlphaNetter who lives with Steve and her two daughters in Maine. She is a support group leader for Maine Alphas and is also active on the national level.

ALA Educational Support Program

The American Lung Association is offering a free educational support program for chronic lung disease patients, their family and friends. The Better Breathing Program is available at 11 locations around Central Florida. Monthly meetings run October through May, and some sites meet year-round.

Topics covered include medications, how to travel with oxygen, how to cope with a chronic illness and much more. The program is free and refreshments are provided.

The program is also available in Spanish. For details, call the American Lung Association of Central Florida at 1-800-LUNG-USA or (407)425-5864.

Netter Notes

Please share any AlphaNetter news with your coordinator for inclusion in future issues of this newsletter.

- ◆ In March, AlphaNetter and Maine support group leader, Viki Reed, spoke at the Maine Respiratory Conference in Rockport, ME.
- ◆ In March, Terry Highland, an AlphaNetter from Littleton, Colorado, completed the Annual 5K Clean Air Challenge in Denver, CO.
- ◆ In May, AlphaNetter, Viki Reed, was awarded the Helen Chase Walsh Award by the Alpha₁ National Association at the annual conference in Portland, OR.
- ◆ AlphaNetter, Julie Swanson, was re-elected to her second term as President of the Alpha₁ National Association.
- ◆ In June, AlphaNet sponsored Dr. Robert Sandhaus as the keynote speaker for the Annual Maine Respiratory Conference held at the Samoset Resort in Rockport, ME. Bayer sponsored a luncheon hosted by the Maine Support Group at the conference.
- ◆ AlphaNetter, Shirley St. Cyr, completed the American Lung Association's "Big Ride" from Seattle, WA, to Washington, DC, on August 1. Shirley St. Cyr was also recognized as an outstanding professional in the field of lung health by the American Lung Association of Illinois who gave her the "Humanitarian of the Year" award.
- ◆ Elizabeth Gadus, an AlphaNetter from Ohio, designed the Alpha₁ Christmas cards this year, sponsored by the Alpha₁ National Association and the Florida A₁ Chapter.



- ◆ AlphaNet and Complete Home Care (from Sioux Falls, SD) sponsored free flu vaccinations for Alphas, their families and friends, at the Alphazonies Southwest Regional Conference this November in Phoenix, AZ.
- ◆ AlphaNet made a contribution to AlphaBeaters in Colorado Springs, CO, for Christmas gifts for underprivileged Alpha Kids.
- ◆ AlphaNet sponsored an informational table and blood screening at the Suncoast Health and Fitness Expo in Sarasota, FL, December 4 and 5. A nurse was on hand to draw blood for A1AD screening. AlphaNetter, Doris Stark, and AlphaNet Coordinator, Marta Strock, were there to supply information, and to encourage people to answer the prescreening questions and have blood drawn. Exhibit space was donated by Suncoast Marketing Enterprises. Supplies to take the blood collection used for screenings were donated by LabCorp. We thank them both for their generosity.
- ◆ Our thoughts and prayers go out to those AlphaNetters who have undergone lung transplant during the past year: Julie Bakula, Sherry Grey, Donald McAmis, Sue Ramseth.

In Memorium. Our thoughts and prayers go out to the families of AlphaNetters who passed away during the last year.

- ◆ Magnus Ball
- ◆ Dennis Cosgrave
- ◆ Tom Downie
- ◆ Billy Harness
- ◆ Jennifer Meredith

NOTE: Please notify your AlphaNet coordinator of any changes in your insurance coverage, nursing services, or pharmacy concerns.

Effective as of January 1999, shipment of Prolastin will be on a 28-day cycle rather than monthly. Call your AlphaNet coordinator for details.

Events Calendar

Please share information about support group meetings or special events with your coordinator for inclusion in future issues of this newsletter.

- ◆ Alpha₁ National Conference will be held Saturday through Monday, May 15 through 17, in Overland Park, KS.
- ◆ The American Lung Association is offering a free educational support program for chronic lung disease patients, their family and friends. (*See the article on page 3 in this newsletter.*)

The Registry

Be Part of the Solution. For those of you who have not already joined the Alpha One Research Registry, an enrollment questionnaire is available by calling 888-825-7421 – ext 215.

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