

The *AlphaNetter* is a publication of AlphaNet, Inc.

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THE AlphaNetter

Coordinator's Corner: A Day In the Life...

By Kay Kinsel

It's 5:50AM MST, Monday morning, and the alarm clock tells me it's time to rise and shine. Actually, I've been awake for a while planning the day's schedule and thinking about things that need to be accomplished. If today is like most Mondays, it'll be a busy one. At 6:05 I roll out of bed, shower and get dressed. I put a few curls in the hair, switch on my PC, and respond to the e-mail that has arrived overnight.

Knowing the critical role that diet plays in my ability to breathe, I understand that breakfast is an important meal, but on the days like today I postpone breakfast until I return from pulmonary rehab. I do my nebulizer treatment, take a few puffs on the inhalers, grab the oxygen and my purse, and I'm out the door heading to rehab by 7:10.

Since no dedicated pulmonary program is currently available at my facility in Laramie, my pulmonologist advised me that cardiac rehab is the next best thing. It's a great way for me to start the week. I go three mornings a week from 7:30 to 9:00AM, with twenty minutes added each way for the twelve-mile drive to and from town. My rehab program starts with a warm-up (I do this before any exercise) followed by twenty minutes on the treadmill, eighteen minutes on the stationary bike and various hand weight exercises. I'm always trying to lengthen my durations! Rehab has improved my physical stamina and mental well-being and I also enjoy the social interaction. The exercise is an excellent opportunity for me to push myself because I know how important it is to stay active and build my strength.

By 9:30 I'm back at my desk and ready to start making phone calls. Every month, I speak with about 200 alphas in seven states, across three time zones. While the folks in Nebraska are up and moving, quite a few are still getting their Z's on the West Coast. I have alphas who prefer to be called at 7:00AM, others who have requested their calls at 9:00PM, and working for AlphaNet from my home has made this flexible call schedule possible. I handle a wide range of questions and issues, usually involving the Bayer Direct program. Conversations with BD subscribers can be very short ("I'm doing fine and don't need anything this month."), or they can be very time consuming. On this day I assist an alpha with her infusion supply order, explain the Bayer Direct program to a recently diagnosed alpha and refer him to a local support group, e-mail health tips to an alpha-caregiver, discuss a nursing care issue with a nurse case manager, mail educational materials, discuss an alpha's insurance problem with a reimbursement specialist, reschedule a ProLactin® shipment, and put an alpha's primary care doc in touch with AlphaNet's medical director. Every conversation is different, but my goal is always the same: to help alphas live their lives to the fullest and stay as healthy as possible, for as long as possible. I think one of the most important parts of my job is just listening to "my" alphas and offering the resources available from AlphaNet, the Alpha One Foundation, the Alpha.1 Association, Express Scripts and Bayer Corporation. I usually end the workday by planning the next, setting out my call schedule, updating my "to-do" list and taking care of my e-mail.

A major benefit of my being an AlphaNet coordinator is that I can work from my home and am no longer out in the general workforce exposed to many common infections. This past winter was my healthiest since being diagnosed in 1994. In my previous employment, I was the director of human resources and office manager and I came in close contact with many employees every day. I truly loved that job and the people with whom I worked, but it was getting more difficult to stay well each year. I live at 7200 ft. above sea level and have used supplemental oxygen 24/7



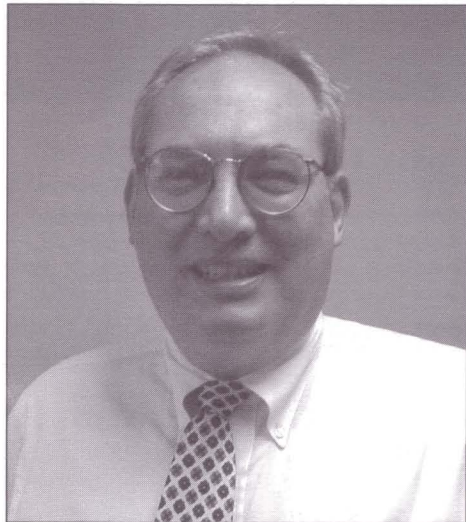
Kaye Kinsel, AlphaNet coordinator for MT, ND, SD, NE, WA, OR, and WY



1st Anniversary Report: Bayer DirectSM

By Robert A. Sandhaus
M.D., Ph.D., F.C.C.P.

AlphaNet Medical Director and
Executive Vice President



Sandy Sandhaus

The Bayer Direct program is approaching its one year anniversary. While this program has met many of its goals, it is necessary to alert the Alpha community to potential Prolastin supply issues that may arise in the future.

History

In the years before Bayer Direct was initiated in November 1999, Prolastin was in short supply. While some patients saw no disruption in their supply of Prolastin, others were forced to reduce or delay doses, and still others had no drug at all. No drug was available for newly diagnosed Alphas. In addition to these events, many Alphas were finding that if they changed insurance, location, and/or physician, their allocation of Prolastin did not follow them.

A better system was needed to allocate and distribute Prolastin more equitably. Members of the Alpha community called for direct allocation of drug to the consumer, bypassing the usual drug distribution network and allowing for portability of their Prolastin prescriptions. In response to these concerns, Bayer designed a system for providing direct consumer allocation of drug combined with optional clinical coordination and disease management by AlphaNet. This overall program was called Bayer Direct.

It was not anticipated that Bayer Direct would relieve the shortage of Prolastin, but that a more equitable distribution would be provided to all whereby avail-

able drug would be distributed in an orderly way to each patient with a Prolastin prescription. As drug inventory was consumed, if more Prolastin was not available, there could be a delay until the next patient on the "wheel" received drug. As soon as new drug appeared, that next patient and subsequent patients would receive drug until the next round of drug was consumed.

When Bayer Direct was initiated on November 1, 1999, there was considerable disruption and anxiety. Those of us that work with AlphaNet want to thank you for your patience and understanding during this trying time. However, once the program was up and running and all who wanted to receive Prolastin were enrolled, something unusual was noticed... there was no shortage of Prolastin! Over the months since Bayer Direct has been operating, there have been minor glitches and problems, but we hope they have been temporary and solved in a courteous and efficient manner. We are extremely proud of the AlphaNet coordinators who have worked tirelessly to solve problems and help make the system run smoothly.

Current Status

Individuals are being diagnosed with Alpha, every day and Prolastin is being prescribed to more and more Alphas. Over the months since the initiation of Bayer Direct, many of us have forgotten that one of its primary goals was the equitable allocation of drug should demand for Prolastin outstrip its supply. While we haven't yet reached that point, we are approaching it, and we at AlphaNet want to be sure that the Alpha community is aware that the potential exists for the "allocation wheel" to be used for its original purpose: the equitable allocation of drug when demand exceeds supply. With an adequate supply of drug, the wheel has no shipping gaps. If Prolastin demand were to exceed supply, the interval between shipments might lengthen (by a day or a week or more) but the shipment size (dosing for four weeks) would remain the same.

An additional factor that can temporarily affect drug supply has to do with variations in Bayer's Prolastin inventory. Prolastin goes through a time consuming and complex purification process. Any lot produced that does not meet the stringent standards set up to ensure the potency and safety of this drug must be

discarded. Thus, Bayer Direct could find itself with a temporary Prolastin shortage, if certain planned lot releases fail in the production process.

In addition, there is a planned production facility shutdown to perform improvements and general repairs. These planned improvements are the result of observations made by regulatory inspections and internal audits performed by Bayer personnel. The shutdown is planned to start in late November and end the first week in January.

These issues are being raised now so that we will all be prepared for future events. The Medical and Scientific Advisory Committee of the Alpha One Foundation will be reviewing patient and physician options during times of reduced allocation. We will be sure to forward this review to you when it is available.

AlphaNet and the Alpha One Foundation are supporting efforts to bring forward and evaluate new dosing methods and new products that can help alleviate potential shortages in the future. We will do our best to advance these as quickly as possible.

As always, should you have any questions please do not hesitate to contact your AlphaNet coordinator for assistance.

Research Registry Update

By Charlie Strange, M.D.

We are excited to announce the Alpha One Foundation Research Registry located at the Medical University of South Carolina is operational. In an effort to promote research for better treatments and a cure for A1AD, we invite you to participate by filling out a new questionnaire as soon as possible. Data included on the questionnaire will be entered into a confidential database that can be accessed only by the Research Registry Staff in Charleston. Further explanation of the benefits and responsibilities of contributing to the alpha community is included with the questionnaire. The small step to fill out a questionnaire assures that you will hear about research trials as they form, yet leaves the decision for further research participation to a later date. To obtain a questionnaire, call toll free 877-886-2383 or email your address to alphaone@musc.edu. We hope we can count on you.

Introducing New Coordinator

Karen S. Lombardo has joined the AlphaNet staff as a new coordinator for California, Idaho, Hawaii and Alaska. Karen worked as a legal secretary for the San Diego County District Attorney's office prior to moving to Moscow, ID where she and her husband currently live. She worked with the Pullman, Washington, Police Department as a records specialist prior to joining AlphaNet.

As AlphaNet coordinator she is committed to helping alphas better understand their condition and become more proactive with their healthcare. Please stop at the AlphaNet booth at SEREAC and say hello to Karen.

— continued, *A Day in the Life...*

since the day after I was accurately diagnosed. The hassles of performing a job while on oxygen and trying to stay away from sick employees was becoming a chore in itself.

When the Bayer Direct began last November, I contacted many alphas who had never spoken with or met another alpha. I remember how frightened and alone I felt after my diagnosis, until I met another alpha and attended my first educational conference. It gave me great hope knowing there were others who shared this disorder, and most of them looked pretty darn good. I will do everything in my power to pass on the love and encouragement I have received from fellow alphas and to be there when they need to talk, or to shake their hand or give them a big hug when we meet.

Alphas are a diverse group and usually don't have much in common other than the disorder itself. I speak with individuals who range in age from twenty-eight to eighty-seven. It is such a wonderful variety of people, from so many different backgrounds, but we have a very important common ground. Being alphas makes us very unique and special people. This has turned out to be a very demanding job, but so emotionally rewarding. Helping other alphas has been a dream of mine for the past four years. When I shut off the lights at the end of the day, knowing that the alphas I have spoken with usually appreciate my help and phone calls, I truly feel blessed. I usually end my day being thankful that I have been able to give of myself to my alpha family.

In Memorium

Nancy Ferguson, 1951-2000

When Nancy Ferguson joined AlphaNet in April 1997, she assumed many roles. She brought her healthcare background to AlphaNet and coordinated the pharmaceutical distribution to the AlphaNet members each month, helping to assure that alphas received timely and adequate drug shipments. Nancy also contributed her business savvy, but never let profitability outweigh her compassion. As one of the first AlphaNet coordinators, she negotiated with insurance companies to extend benefits to "her members" and was a tireless advocate for all those affected by alpha₁-antitrypsin deficiency. Nancy was never too busy to speak with a newly diagnosed alpha or to offer her advice to anyone who sought it.

Nancy performed all her roles well. Her commitment to her fellow alphas helped pave the way for AlphaNet's growth and development. Her contributions were immeasurable and will never be forgotten.



Those of us who worked with Nancy, as well as those of us she helped, miss her dearly. She was a kind and loving friend who was taken from us much too soon. Nancy Ferguson was the embodiment of our purpose, "Alphas Serving Alphas."

International Scientific Conference

Alpha₁-Antitrypsin Deficiency and Other Conformational Diseases

The Second Annual Scientific Conference convened by the Alpha One Foundation was held at the Airlie Conference Center in Warrenton, VA, June 27-30, 2000. Conference participants represented a cross section of the Alpha medical, scientific and patient communities. In attendance were representatives from prominent research institutions in England, Ireland, Scotland, Sweden, Austria, Switzerland, Germany, Italy, Canada, Australia and the United States. Also included were representatives from the FDA, NIH, American Red Cross, Alpha 1 Association, and pharmaceutical companies. Alphas who attended included Nancye Buelow, Fred deSerres, Sally Everett, Bettina Ervine, Joe Reidy, Cathy Valenti and John Walsh.

This conference was particularly timely in light of the recent announcement about the completion of the first phase of the Human Genome Project. According to Dr. Richard N. Sifers, Ph.D., "the complete mapping and sequencing of the Human Genome will not only provide us with invaluable data, but will also focus attention and resources on protein research—where many of us believe the key to cures for a wide range of diseases will be found."

AlphaNet Medical Director, Sandy Sandhaus said many scientists commented about the difference it made that there were actual alphas in attendance; putting a face on the condition being discussed elevated the conference a step above other conferences many participants had attended.

A conference highlight was the awards dinner which was held the first evening. Leopoldo and Marilina Fernandez were recognized for their generous donation to the Foundation and the newly established Fernandez Liver Research Initiative was announced. The Alpha One Foundation and the American Liver Foundation also announced the first recipients of the Alpha One Foundation Innovative Seed Grant for research in liver disease associated with A1AD. Award recipients were Jeffrey Teckman, M.D., Department of Gastroenterology, Washington University School of Medicine, and Mark A. Zern, M.D., Department of Internal Medicine, Director, Transplant Research Institute, University of California, Davis. These awards, in the amount \$100,000 over a 2-year period, are the first matching grants between the American Liver Foundation and the Alpha One Foundation.

For more information about the conference, contact the Alpha One Foundation.

Netter Notes

- ◆ Millie Felci, an alpha from Weymouth, MA, has organized a daytime support group. The hope is to provide a venue for alphas who can't make the Thursday night support group meetings sponsored by the ALA. South Shore Hospital has been instrumental in providing the time and space to make her effort a reality. For further information call Millie at 781-335-2641 or e-mail at jpfelci@mediaone.net
- ◆ In May, the Alpha 1 Association Annual Conference, was held in Charlotte. Pictured below are two familiar AlphaNet coordinators receiving awards from the A1A, Mary Pierce and Gayle Allison.



Alpha 1 Association Annual Conference 2000 in Charlotte, NC: Dick Bueker and Pat MacInnes at the AlphaNet booth.

- ◆ On July 22, AlphaNet coordinator Kay Kinsel met with eleven alphas and their families at a dinner hosted by Bayer Rep, Joe Blaesing, in Omaha, NE.

On July 23 Kay traveled to Watertown, SD to another get together with seven alphas and their family members. This group will get together again September 10 to start a support group.

On July 31, another 4 alphas and their families met near Grant Island, NE for a dinner also hosted by Bayer Rep, Joe Blaesing.

"Having the opportunity to meet so many alphas that I speak with on a regular basis was very special for me." Kay thanks her daughters, Stephanie and Sherry, and her sister Mary for hauling the boxes of educational materials to and from the events, and for making this trip possible.

- ◆ August 25, 2000. A Down East lobsterfest was held in Warren, ME to kick off alphas' participation in the *Five Points of Life Ride 2000*. Vickie Reed and her family hosted the event for over 100 alphas, their friends and families. Bayer provided the "maine" course, a steaming seaweed covered table stacked with lobster, and steamed clams and muscles. Bayer was represented by Dave Colburn, the local Bayer Rep and Biological Account Executive, Rick Lee, the Northeast Accounts Manager, and Mike Gabay, the Southeast Accounts Manager. Thanks also for contributions from The Alpha One Association and the Alpha One Foundation. Alpha troubadour Eric Hanson provided the musical entertainment for the evening. Special thanks to Vickie, Steve, Rachel, Chelsea and extended family for their tireless efforts. Bravo!

Events Calendar

- ◆ Five Points of Life Ride 2000—August 26 to October 18—bike trek from Bar Harbor, ME, to Key West, FL. The ride is to promote awareness for the importance of organ and blood donation.
- ◆ Autumn Escape 2000—September 15-17—bike trek from Plymouth to Provincetown, MA. American Lung Association fundraiser for lung research and to promote awareness.
- ◆ Georgia Support Annual Picnic, September 16 at Lake Alatoona. For information, call Gayle Allison 877-982-5742.
- ◆ Annual Southeast Regional Alpha-1 Educational Conference (SREAC), Saturday, October 20 in Nashville, TN. For further information call Allana at the A1A: 952-703-9979.
- ◆ The 4th Annual Southwest Regional Educational Conference, Saturday, November 18, from 7:30-4:30, will be held at the Best Western Grace Inn, 10831 S. 51st Street, Phoenix, AZ 85044. Early registration and welcome reception Friday evening, 5-8 pm. For information call Judy Rose at 520-319-0948.

Flu Season

Free flu shots will be available at both regional conferences this year sponsored by AlphaNet. Make sure you get your flu shot and ask your coordinator for health tips and updates.

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

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Return Service Requested

