

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

Editorial Office:

AlphaNet, Inc.
2937 SW 27th Avenue, Suite 305
Coconut Grove, Florida 33133

How to Contact AlphaNet:

Phone: 1 (800) 577-2638 + ext.*
Fax: 1 (305) 442-1803
Website: <http://www.alphanet.org>

Staff:

Robert C. Barrett – ext. 229*

Chief Executive Officer

(800) 577-2638

Janis G. Berend, MSN, C-ANP – ext. 220*

Director of Nursing

(800) 577-2638

Geovannia R. Bequer – ext. 209*

Accountant

(800) 577-2638

Bonnie S. Boyd, R.N. – ext. 255*

Director, Disease Management and Clinical Research

(561) 969-9454

Jill C. Jensen – ext. 243*

Administrator, HR & IT

(800) 577-2638

Kathleen M. McKay, R.N. – ext. 212*

Nursing Coordinator

(877) 913-8141

Robert A. Sandhaus, MD, PhD – ext. 226*

Medical Director and Executive Vice President

(800) 577-2638

Trina F. Stephenson – ext. 443*

Information Manager

(800) 577-2638

Terry L. Young – ext. 514*

General Manager

(800) 278-1804

Rosemarie Z. Carrillo – ext. 254*

Administrative Assistant

(800) 577-2638

Coordinators:

Gayle Allison

NC, VA, WV, DC (877) 982-5742

Patti Brown

East TX (877) 264-7470

Dick Bueker

Coordinator at Large (816) 943-9828

Victoria Cameron

ME, NH, VT (888) 526-9077

Bob Campbell

FL, USVI, PR (888) 399-0443

Shirley Dennis, LPN

MN, WI (877) 662-4774

Joyce Finch

MI (888) 225-9012

Phil Freeman

AZ, NM, OK, WestTX, UT (866) 866-0330

Kathy Haduck

PA, MD, DE (800) 813-4494

Randy Harwell

TN, GA, SC (866) 762-1850

Kay Kinsel

MT, NE, ND, SD, WY, CO (877) 742-9078

Pat Macinnes

NY (877) 277-7931

Darrell Nail

Coordinator at Large (800) 837-4244

Diana Patterson

LA, AR, MS, AL (866) 556-6622

Mary Pierce

KY, OH (888) 883-2991

Judy Rose

Coordinator at Large (877) 860-8694

Sandy Singleton

AK, CA, HI (877) 898-8630

Kathie Sivesind

NV, WA, OR, ID (866) 244-1026

Doug Turley

IA, KS, MO (877) 943-9828

Liz Veronda

IL, IN (888) 723-9487

Fred Walsh

Medicare Specialist
MA, RI, CT, NJ (800) 791-3194

THE

AlphaNetter

Bayer Direct Patient Satisfaction Survey Results

Summarized by Trina Stephenson, Information Manager

The latest Bayer Direct Patient Satisfaction Survey* was conducted by Harbaugh Associates of Exeter, NH on behalf of AlphaNet, Inc., during late November and early December 2001. The survey focused on the level of satisfaction that people have with specific aspects of the Bayer Direct program and on obtaining community input regarding current issues. This article will focus on some of the consensus results regarding Prolastin® supply issues.

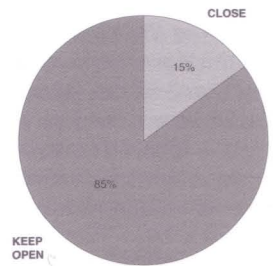
A mail survey was used as the research method to collect these findings. A total of 871 patients completed the survey for a response of 34.8% which is a high response rate. This report reflects the views of over 1/3 of all Alpha-1 patients receiving Prolastin® through the Bayer Direct program in the United States.

Patients were asked about the Prolastin® supply situation and how they suggest it should be handled given that the demand for product exceeds Bayer's production capacity.

How to Handle Supply Situation

(If Average Shipment Interval of a 4 week supply of Prolastin® is Less Than 35 Days)

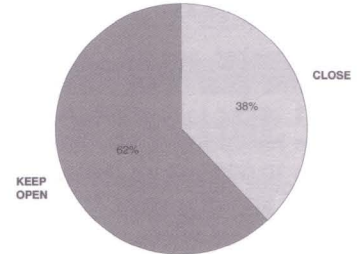
If the average interval between shipments is less than 35 days, 85% of patients feel that the Bayer Direct Program should remain open to new enrollees.



How to Handle Supply Situation

(If Average Shipment Interval Reaches Between 35 and 39 Days)

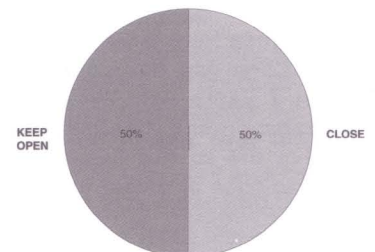
As the average interval between shipments increases, more patients feel that the program should be limited to those already enrolled. If the average interval between shipments were to reach between 35 to 39 days, 62% of patients feel that the Bayer Direct Program should remain open to new enrollees.



How to Handle Supply Situation

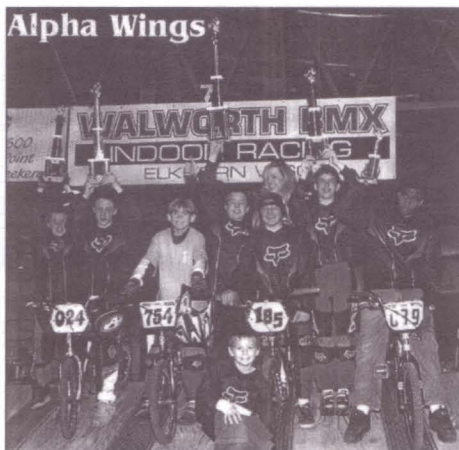
(If Average Shipment Interval Reaches 50 Days)

If the average interval between shipments reaches 50 days, 50% of the respondents feel that the Bayer Direct Program should be kept open to new enrollees.



*A 10 page summary of the survey results is posted on the AlphaNet web site at: <http://www.alphanet.org/news.htm>

Ride On!



The "Alpha Wings" BMX team was founded by Michelle and Ed Eymer, and their three sons, Jayson, Jon and Mat. Ed Eymer was diagnosed with Alpha-1 five years ago.

The "Alpha Wings" was formed in the Spring of 2001 by a group of kids with a strong interest in BMX racing. They decided to start a team to help promote awareness of Alpha-1 in honor of their family and friends who have the disease. Six of the team members are MZ carriers of Alpha-1.

"Alpha Wings" raced at two local tracks (Lake County in Grayslake, IL and Wilmot Mountain in Wilmot, WI) and placed as one of the top 4 teams at these local track series. Some of the team members even ventured further and gave their talent a try at the Grand National in Louisville, Kentucky where they were able to promote awareness of Alpha-1 to many spectators.

Three New Coordinators Hired

In January 2002, three new AlphaNet employees began addressing the needs of Bayer Direct subscribers.

Robert Campbell

Bob was in the newspaper business, both as a circulation district manager for the St. Petersburg Times and previously as a reporter and editor, before joining AlphaNet. He was correctly diagnosed by an allergist in the summer of 2000 after being treated since childhood for asthma. He lives in Brandon, Florida, with his wife Elizabeth and son Max. He assists Bayer Direct Subscribers in Florida, the Virgin Islands, and Puerto Rico.

Sandy Singleton

Sandy lives in Ashland, Oregon. She was diagnosed in 1995 while working for a pulmonologist. Prior to joining AlphaNet, she worked in the medical field for eleven years. She has a 19-year-old daughter attending college in Sacramento, California. She enjoys walking her golden retriever Duke, antiquing and reading. Sandy is responsible for facilitating the care of alphas residing in the states of California, Hawaii and Alaska.

Kathleen Sivesind

Kathie was diagnosed in 1993 and lives with her husband and 2 miniature schnauzers on Camano Island in Washington State. Prior to joining AlphaNet she worked in the medical insurance field for over 20 years and also worked in the travel industry for short while. Her daughter, son and 3 grandchildren also

live in Washington. Kathie enjoys traveling, gourmet cooking, golfing and boating. She is responsible for serving alphas in the states of Nevada, Washington, Oregon and Idaho.

Detour

by Elizabeth Gadus

"You've been here before," he said.

Don't be afraid.

"There's a roadmap on the seat and a bible in the glove compartment if you don't trust my directions."

But, to me,
the road looks different this time.

No roadside rests
void of the usual population
decorating other travels
I seek lost landmarks.

Water filled ruts —
my tires sink deep in mud
so I stop and grab the map
and look out over the dash
into a cracked windshield
for signs.

And I wonder
when will it feel familiar
familiar enough to relax
familiar enough to endure the ride.

Into the Blue

Jeff Meeker, age 32, fulfilled a personal lifetime goal of skydiving in August of 2001. After taking off in a small plane from Newport RI, and taking the plunge from 10,000 feet up, Jeff reported he was more apprehensive about the ride up than the ride down. He was euphoric after touching down and immediately began planning the next family adventure — parasailing off the coast of Newport, RI.

Jeff comes from a family of alphas. His sister Chris, who had a double lung transplant 2 years ago, recently resumed horseback riding. Like Jeff, she continues to live life to the fullest. The whole Meeker tribe attended the "Autumn Escape" Plymouth to Provincetown bike trek last September.



Jeff Meeker (below his instructor) in freefall before pulling his parachute cord.

Life After Transplant

A Conversation between Trina Stephenson, Information Manager for AlphaNet and Shirley Dennis, AlphaNet Coordinator for Minnesota and Wisconsin.

AlphaNet Coordinator Shirley Dennis is back to work after having a double lung transplant in April 2001!

Q: What were your biggest concerns when you decided to get a transplant?

"Death from the surgery was pretty big on my list of anxiety factors. I knew that it was a risk but, finding myself more and more compromised by Alpha-1, I resolved that the benefit of transplantation outweighed the risk. One of my other fears was waking up on the ventilator. I did indeed awaken several times, fighting the vent and it was not pleasant but it was tolerable, and they medicated me to keep me knocked out until they were ready to pull the tube."

Q: What do you think was the most important preparation you made to get ready for the transplant?

"I feel for my own purposes there were several areas that need to be attended to while waiting. I first secured my health insurance. Maintaining the best health you can, using diet and exercise as tools, helped me accomplish much more than expected for a person with lung function at 18 percent. Finally, cleaning up any unfinished personal business provided me with peace of mind. By this I mean having someone you trust know where to find your financial records and checkbook. I wrote out my checks with no date on them for monthly expenses. If I needed to be in the hospital any great length of time, this person could simply date my checks and my bills would be taken care of for another 30 days. This person also knew my end of life wishes, what life insurance policies I held, and what important people needed to be notified. I made a "tree" of people to call, which contained their name, position/relationship to me, phone number, address, e-mail, etcetera."

Q: Is there anything you would do differently now to prepare for the transplant?

"No, I don't think I would have done anything differently."

Q: Would you have accepted a single lung transplant if that was offered to you?

"Yes, I would have accepted a single. Actually my first "dry run" was for a right lung and I was ready. My listing status was, right, left or bilateral."

Q: What made you choose the transplant center that you selected?

"When I was first diagnosed in 1993, I was referred to Loyola immediately. I did look into other centers regionally, like Freodert in Milwaukee, and the University of Wisconsin at Madison, but when I decided to list on April 5, 1999, I decided that I felt very comfortable with the staff at Loyola. They knew my case from the start, and they were having very good success rates with lung transplants."

Q: Is there any particular thing that your transplant center did extremely well or that you would look for in any transplant center?"

"I feel that they treated me as a whole person, not just treating my lungs. They talked openly about my status, encouraged my participation in my care and they supported my determination to maintain my independence."

Q: Do you ever think about the donor?

"Yes, I do think about her. I have not written to her family yet though. I am so grateful for them, but think that since my donor was only 15 the family may still be mourning her loss, with the passing of each season, and holiday. I plan to write them a letter on my 1st anniversary. I think then it will be easier for them to share my happiness."

Q: How is your life different today than if you had never had a transplant or been sick with a genetic disease?"

"It's hard to say where my life would have taken me without having Alpha-1 and the transplant. I was looking forward to continuing my career as a nurse, which now is frowned upon by the transplant center. I learned so much about people and the human spirit because of being sick, so although it changed my plans, my life is very full and I feel I am a richer person due to my experiences."

Q: What parts of care post transplant are hard and which are easy?

"I would say the easy part, despite what the transplant centers tell you, is taking the medications. They scare you into thinking you'll do nothing but watch the clock and take fistfuls of pills all day long. I got a seven-day pillbox; each day contains four compartments, morning, noon, evening and bed. The day boxes are removable from the base. Each Saturday I get out all my bottles, and load up the pillboxes. This way I can take a day's worth of medicine and go away for the day, which prevents accidentally forgetting a dose."

The hard part for me is the food restrictions. I am on Prograf and this means no legumes. I love black beans, baked beans, pea pods, and peanut butter. All



Shirley Dennis, in September of 1999, at the ALA-sponsored Autumn Escape Bike Trek on Cape Cod, MA.

are forbidden to me now. If it grows in a pod it is a legume."

Q: Was there a lot of pain, how long were you in pain, how was it managed?

"I may have a high pain threshold, but no the pain wasn't too severe... really! They used an epidural in the hospital to deliver pain medications. Once they took out the epidural I was put on Vicoden, which adequately suppressed the incisional pain so that I could deep breathe and cough as ordered. I remember only being in prolonged pain on my first night home. My transplant coordinator called in a script for Vicoden to my pharmacy, and I was supposed to pick it up on my way home, unfortunately the pharmacy closed before I was discharged. I had 2 Vicoden from the hospital, and I took one with 2 Extra Strength Tylenol each 4 hours until the pharmacy opened at 8 am. I used Vicoden for 2 weeks then just Tylenol."

Happy Anniversary Shirley. Many more.

Patient's Corner

This is a regular column that features short vignette on how Alpha-1 patients are coping positively with the disease. If you have a story to share, please contact your AlphaNet Coordinator for possible inclusion in a future column.

Our inspiration this month comes from a Bayer Direct patient in Indiana. Liz Veronda, AlphaNet Coordinator for Illinois and Indiana reports that Wilma Brown walks 2 miles everyday on a treadmill! She said she was motivated by the *AlphaNetter* and it's articles that stressed how important exercise is for us!

Events Calendar

Alpha-1 Education Day / June 22, 2002.

Provena St. Joseph Medical Center College Of Nursing, 333 N. Madison St. Joliet, IL For overnight accommodations, call: Holiday Inn Express, 411 S. Larkin Ave, Joliet, IL 60436; phone 815-729-2000. Rates are \$62.00 plus 13%tax. To make reservations for the conference, please call Liz Veronda at 1-800-723-9487 or email: lveronda@alphanet.org

Support Group Meetings:

- April 13, 2002 / Capital Area Alpha will meet at Chapel Hill public library. For more information call Gayle Allison toll-free at 877-982-5742.
- April 13, 2002 / West Virginia Alpha-1 Educational & Support Group, Hurricane, WV. For more information, call Gayle Allison toll-free at 877-982-5742.
- April 18, 2002 / Massachusetts Support Group, Thursday from 7:30-9:30PM at the Wingate in Needham. Dr Edwin Silverman of Harvard University and Brigham & Women's Hospital will talk about the Alpha-1 Foundation and NIH funded sibling study (genetic modifiers of Alpha-1). For more information call Fred toll-free at 800-791-3194 or Martha (ALA) at 508-668-6729.
- April 20, 2002 / Connecticut Support Group meeting, Saturday at 1:00PM in the Chauncey Conference Center, Gaylord Hospital, Wallingford, CT. Guest speaker (clinical nutritionist) Gilbert Saltman: "Good Nutrition for Liver & Lung Affected Alphas." For more information call Ruth at 203-452-0122. For directions call 800-647-3422 (Gaylord Hospital).
- April 20, 2002 / Virginia Alpha-1 Support Group meeting at Virginia Beach. All

alphas from surrounding areas invited. For more information call Gayle Allison toll-free at 877-982-5742.

- April 27, 2002 / Memphis, Tennessee Alpha-1 Regional Support Group Meeting starting at noon. Featured speaker: Robert A. Sandhaus, MD, PhD. Bayer Pharmaceutical Division will be providing lunch. We will have at least one Bayer rep on hand, and a representative from the Alpha-1 Association. Call Diana Patterson toll-free at 866-556-6622 or Randy Harwell toll-free at 866-762-1850 for location and other details.
- May 4, 2002 / Carolina Alpha-1 Support Network will meet in Greensboro, NC. For more information call Gayle Allison toll-free at 877-982-5742.
- May 8, 2002 / Alpha Opportunities of Southeastern Pennsylvania will meet at 10:30AM at the Temple University Hospital Pulmonary Unit. The subject will be insurance laws and questions relevant to the Alpha Community. For more information call Kathy Haduck toll-free at 800-813-4494.
- May 17, 2002 / West Chicago, Illinois support group will meet 7:00 to 9:30 PM at the home of Leroy and Maria Fennewald, 1055 Willow Creek Rd., West Chicago, IL. Contact the Fennewalds, 630-231-8780, or Sylvia Moore, support group leader, at 630-585-8378, or email to: galiana-inc@msn.com
- May 22, 2002 / Cleveland Clinic Support Group, Fairview Hospital from 7:00-9:30 PM in Meeting Room A, 18101 Lorain Ave, Cleveland, Ohio 44111. For more information contact 216-476-7000.
- June 15, 2002 / Peoria, Illinois support group will meet from 11:00 AM to 3:00 PM, at Peoria Pulmonary Group, 214 NE Glen Oak Avenue-Suite 502. Parking is free at the Methodist Hospital parking deck.

Contact David Aberle, Support group leader at (309)387-2353 or email: A1lung@msn.com.

- June 19, 2002 / Cleveland Clinic Support Group, Summa Health System, will meet from 7:00-9:30 PM, Akron City Hospital Campus, Professional Center South, POD-A, 55 Arch Street, Akron, OH 44304; phone contact 330-375-7940.
- West Michigan Alphas will be meeting once again this Spring and Summer! We are hoping to meet in several different cities to meet alphas and reorganize! Please call Joyce Finch at 1-888-225-9012 for further details.

Other Events and Conferences:

- June 6, 2002 / Alpha-1 Advocacy Day, Capitol Hill, Washington D.C. AlphaNet has made a limited number of transportation and lodging scholarships available through the Alpha-1 Association. Call the Association at 1-800-521-3025 for additional information.
- June 7-9, 2002 / Alpha-1 Association National Conference in Tysons Corner, VA. For more information contact the Alpha-1 Association at 1-800-521-3025.
- June 26-29, 2002 / US Transplant Games, Disney's Wide World of Sports Complex in Orlando, FL. AlphaNet Coordinators Shirley Dennis, Randy Harwell and Mary Pierce will be competing.
- September 20-22, 2002 / Team Alpha-1 at the "Autumn Escape to the Cape" bike trek sponsored by the American Lung Association of MA.

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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AlphaNet, Inc.
2937 SW 27th Avenue, Suite 305
Coconut Grove, Florida 33133

Return Service Requested

