

The AlphaNetter is a publication of AlphaNet, Inc.

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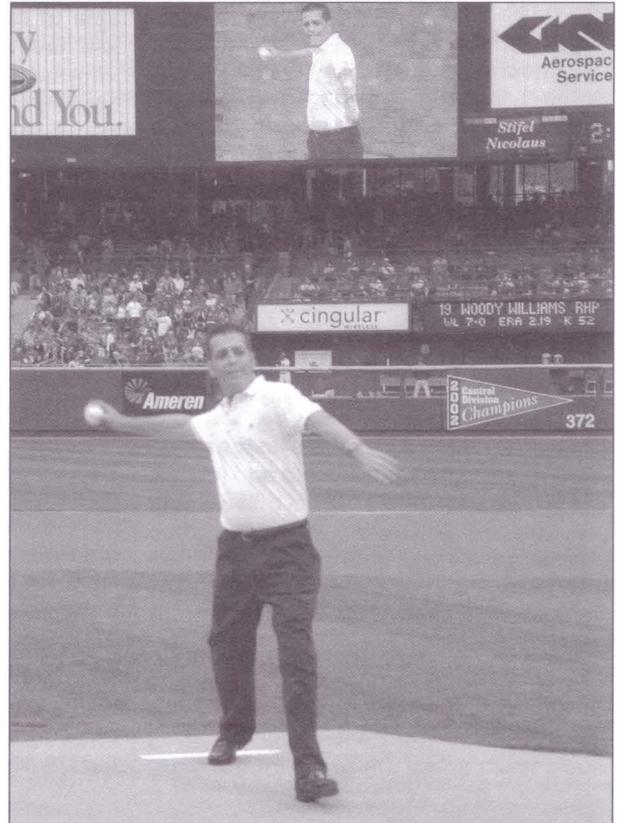
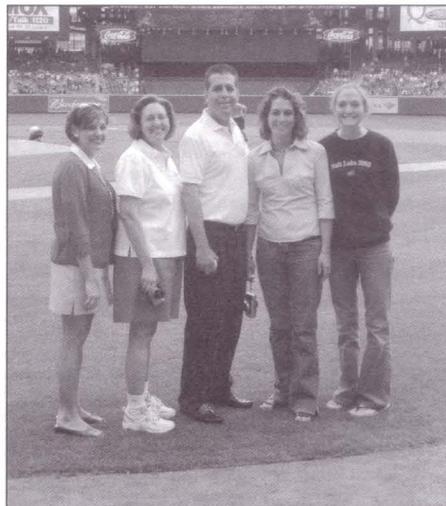
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THE AlphaNetter

All-Star Delivery

AlphaNet Coordinator Darrell Nall took time out from the Alpha-1 Association's Annual Educational Conference and delivered the first pitch at the St. Louis Cardinals-Pittsburgh Pirates baseball game at Busch Stadium on May 31, 2003.

Darrell was selected to represent the Barnes Medical Center Transplantation Program on the field because of his athleticism, rapid post-surgical recovery and positive outlook. He underwent bilateral lung transplantation in February 2003.



◀ Pictured on the field are (L to R) Candance Cundiff, the Activities Director at Barnes Jewish Hospital; Joellyn Nall, Darrell's wife; Darrell Nall; and Sarah and Erin Nall, Darrell's daughters.

On the Road With Team Alpha in Wisconsin

It rained for two of the American Lung Association's 3-day Lake Tour Bike Trek, June 6-8, in Lake Geneva, Wisconsin. 150 riders participated in the 150-mile tour; Team Alpha dominated with over 30 members either riding or volunteering as S.A.G. (Safety and Gear) drivers. AlphaNet Coordinator Liz Veronda captained Team Alpha-Illinois this year for the first time, bringing the largest Team Alpha ever for this event. This was Team Alpha's 8th appearance at the Lake Tour since 1996. They collected the most pledges as a team, bringing in \$9901 for the American Lung Association.

Team Alpha took awards for the biggest team, the youngest team rider at 8 years old, and the oldest rider who used her oxygen while riding! They provided 2 motorcycles for the S.A.G. effort with recently lung transplanted AlphaNet Coordinator, Darrell Nall, and his bother-in-law Steve, keeping track of the bicyclists on the road from the saddles of their Harleys.

The Trek began Friday morning, June 6th at McHenry College in Crystal Lake, IL, and meandered 50 miles to the Grand Abbey Resort in Lake Geneva, WI. Although it rained most of the day, trekkers persisted to the finish, hoping for a few minutes in the hot tub before the BBQ started.

— continued on page 2, column 1



AlphaNet
Alphas Serving Alphas

Alpha-1 International Patient Congress

By Gayle L. Allison, AlphaNet Coordinator
What an experience!

My first trip out of the country was to represent AlphaNet at the very first Alpha-1 International Patient Conference, held in Barcelona, Spain.

During the month of June, I joined 44 other patient representatives from 14 countries to help one another through discussions about patient issues such as available therapies, treatment options, support systems and registries.

Our meeting coincided with the annual Alpha-1 International Registry meeting for physicians and researchers. We were very fortunate to be able to attend the scientific sessions and, in return, to have about 30 physicians and researchers join our meeting. Other patient group representatives from the US included Greg Hules representing the Alpha-1 Foundation and John Morton from the Alpha-1 Association. While at the conference, I conducted a focus group discussion for an anonymous healthcare firm. The nine participants (from nine different countries) in the group were so animated, passionate and intense about various Alpha-1 issues that we simply could not stop talking. When the group concluded, we kept going; and from those discussions a new entity was born—the Alpha-1 International Network (AIN).

The goal of the AIN is to help share information through regular communication among Alphas internationally. We have a representative from each country (Greg Hules was named the rep from the USA)

and I was honored to be selected co-chair, along with chairman Larry Warren of Ireland. We are developing a newsletter that can be distributed both electronically and by a traditional printed version. The newsletter will be able to be translated from English and will have a template for country-specific information. All of us involved are extremely excited about the potential of AIN. We've already started working and promise updates on our progress, to the entire Alpha community, in the near future.

Having the incredible opportunity to speak with other Alphas from around the globe really showcased just how variable our care and treatment can be from country to country. There are thousands of Alphas around the world who remain unidentified and untreated and many who are diagnosed are not part of a registry

This conference really made me understand just how lucky we are in the US to have the tremendous organizations and physician support that we have. We take so much for granted. Dr. Sandhaus is my personal hero for all he does for every Alpha, as well as for quickly assessing I had developed a cough while in Spain and taking swift action to get it under control.

I was honored to represent AlphaNet and the US Alpha community.



Upcoming Alpha-1 Education Days

Produced by the Alpha-1 Foundation and the Alpha-1 Association

- **August 9-10, 2003**
3rd Annual Alpha-1 Education & Research Conference
National Jewish Medical & Research Center, Denver, CO
Contact: Janis Berend (303) 398-1858
jberend@alphanet.org
- **August 16, 2003**
3rd Annual New England Alpha-1 Education Day
Dartmouth Hitchcock Hospital
Lebanon, NH
Contact: Shirley Dennis (877) 662-4774
sdennis@alphanet.org
- **October 4, 2003**
Virginia Alpha-1 Education Day
Lewis-Gale Foundation
Salem, Virginia
Contact: Gayle Allison (877) 982-5742
gallison@alphanet.org
- **October 11, 2003**
The Jean Bennett Conference on Alpha-1
Cleveland Clinic Foundation
Cleveland, OH
Rick Rice, R.R.T. (216) 444-2140
Email: ricer@ccf.org
- **October 17-18, 2003**
COPD and Alpha-1 Education Conference
The James P. Mara Center
St. Luke's Roosevelt Medical Center
New York City, NY
Lori Tartell (212) 523-2828 ext 2566
LTartell@chpnet.org
- **October 18, 2003**
Texas Alpha-1 Education Day
University of Texas at Tyler, Dallas, TX
Contact: Lou Glen (817) 477-5430
e.lou.glen@worldnet.att.net

Alpha-1 Education Days are sponsored by Aventis Behring, Baxter Corporation and Bayer HealthCare.

—continued, *On the Road with Team Alpha*

Day two was a beautiful, sunny fifty-mile trek around the lake with a chance to swim at one of the rest stops. That evening trekkers enjoyed prime rib and



Left to right: Mary Pierce, Darrell Nall, Wilma Johnson (front), Ken Walkley (back), and Liz Veronda.

chicken followed by fund raising awards. Day three brought several sudden weather changes, first sun, then within minutes, cloudiness, cold, rain, hail and back to sunshine. It was tough on the riders, especially after riding the first two days. They were exhausted, tired, sore, and wet but still determined to finish. The very last riders of the day were predictably from Team Alpha.

With lots of new riders and fund raising this year, Team Alpha made a huge splash and plans to do even better next year. They hope to negotiate a deal for all the money raised for the American Lung Association going directly to programs for Alpha-1.

If you are interested in joining Team Alpha at the Lake Tour next year, either as a rider or volunteer, please contact Liz Veronda, Illinois Team Captain, at 888-723-9487.

Upcoming American Lung Association Bike Treks

- September 5-7, Lakeshore Loop, American Lung Association of Michigan.
- September 19-21 Great Escape to the Cape, Massachusetts.

Call Mary Pierce, AlphaNet Coordinator, for information: (888) 883-2991

Alphas Give High Marks to Support System

Program Satisfaction Reported Via AlphaNet Sponsored Survey

Coconut Grove, Fla., June 16, 2003— A recent survey completed by Alpha-1 Antitrypsin Deficiency (Alpha-1) patients shows an all-time high in patient satisfaction with the Bayer Direct™ program and the services provided by AlphaNet, Inc. In fact, the average overall satisfaction score totaled 4.4 on a scale of 5.0. The findings show the program, which provides pharmacy, reimbursement, communication and support services, is meeting patient service expectations across the board.

AlphaNet, Inc. sponsored the survey in order to measure patient satisfaction with the Bayer Direct™ program. AlphaNet, Inc., a not-for-profit organization dedicated to providing support programs for Alpha-1 patients, employs 24 people who are living with Alpha-1, a rare genetic disease that may predispose affected individuals to develop emphysema, liver disease, and panniculitis, a skin disease. The World Health Organization (WHO) estimates as many as 100,000 Americans have severe Alpha-1, though fewer than 10 percent have been identified. Prolastin®, a treatment available to Alpha-1 patients, is manufactured by Bayer Biological Products and distributed through Bayer Direct™.

Robert C. Barrett, chief executive officer of AlphaNet, Inc. said, "These results are exciting, not only because they show that our program is succeeding in meeting the needs of our patients, but also because we continue to improve upon already-high satisfaction scores. Serving the Alpha-1 community continues to be our number one priority."

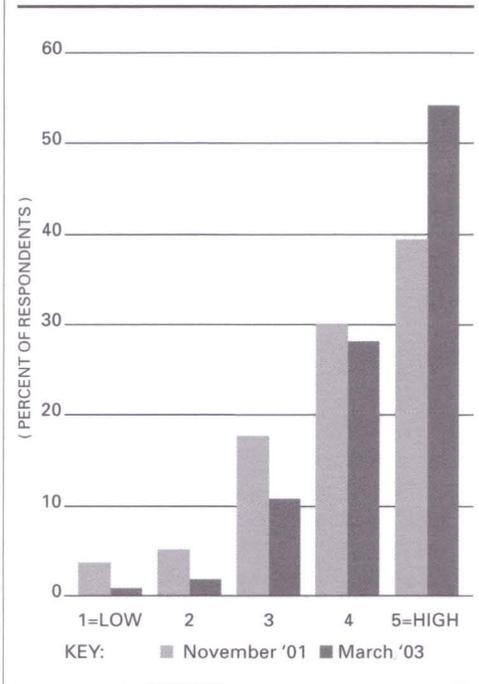
Quantitative results showed patient satisfaction was high in each category, and

numbers were as high as, or higher than, those of a similar survey conducted in late 2001. Categories studied included consistency of product pricing, level of support and understanding received, performance of pharmacy services, performance of reimbursement specialists, nurse case manager performance, AlphaNet Coordinator performance, frequency of contact, and overall satisfaction. In each category, results showed that Alpha-1 patients are pleased with the Bayer Direct™ program with an average score of 4.4 out of 5.0 overall.

In comparing the 2001 and 2003 surveys, the following highlights were noted on a 1 to 5 scale where 5 was the highest level of satisfaction:

- Overall satisfaction with the Bayer Direct™ program increased from 4.0 in 2001 to 4.4 in 2003.
- Increased satisfaction with reimbursement specialists. The average score in 2003 was 4.3, up from 4.0 in 2001.
- Increased satisfaction with services provided by AlphaNet Coordinators. The average Coordinator performance satisfaction score was 4.8 in 2003, up from 4.6 in 2001. More than 87% of survey participants were in regular, monthly contact with their AlphaNet Coordinator.
- Increased satisfaction with pharmacy services. Those responding gave an average of 4.5 to pharmacy services in 2003, up from 4.4 in 2001.
- Over 93% of respondents agree or strongly agree that the Bayer Direct™ program provides access to Prolastin® even if the patient moves or changes physicians or insurance companies.

Satisfaction of Service Personally Received From Bayer Direct



Barrett noted that the survey provides valuable feedback on ways to improve satisfaction and meet patient needs. "I am pleased with these overwhelmingly positive results. Increased satisfaction in every category is not only a positive reinforcement for us as employees, but our hope is that it is also reaffirming for Alphas we serve. Our focus will continue to be further improvement in our services to the Alpha-1 community," Barrett said.

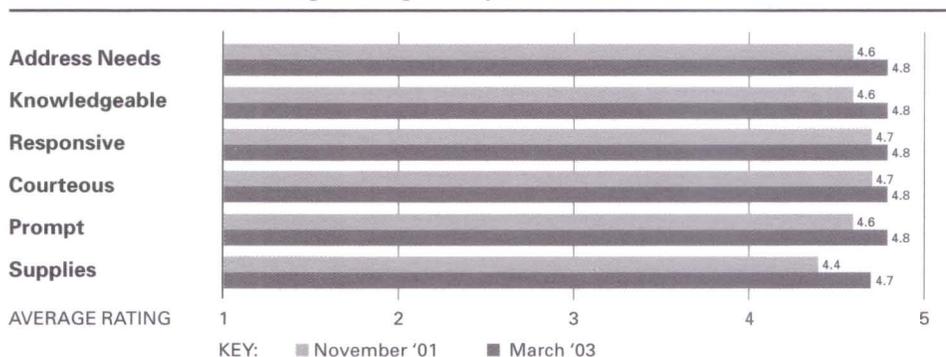
Survey Methodology

Harbaugh Associates conducted the Bayer Direct™ patient satisfaction survey on behalf of AlphaNet, Inc. during March 2003. A total of 959 patients completed the survey, representing 38.9 percent of the mailed questionnaires. A previous survey was conducted in November 2001.

AlphaNet, Inc. and Bayer HealthCare LLC recently agreed to extend their Disease Management Agreement. Through this relationship, AlphaNet Coordinators will continue to provide a wide range of services to Bayer Direct™ subscribers through October 2009.

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

Average Rating* of AlphaNet Coordinators



*Based on a rating of 1 to 5 where "1" is low satisfaction and "5" is high satisfaction.

An Alpha Celebration—Astrid Hudson turns 90!

By Kay Kinsel Swift, Alphanet Coordinator

Astrid Hudson, at 90 years young, is an inspiration to all Alphas. Many in her large family of three children, eleven grandkids and nine great grandchildren visited to help celebrate her special day on January 18th.

Still living alone, Astrid was first diagnosed at age 75 after noticing she was having trouble breathing while pushing her lawnmower. She has lived for 86 years on farms in Nebraska, but now lives in the town of Gothenburg. Always physically active, Astrid even did her own housekeeping up until the last couple of years when she began to require full-time oxygen.

These days she is still an avid reader and radio listener, always asking questions



and wanting to know about the latest research to benefit Alphas. None of Astrid's family members have been diagnosed with Alpha-1 or emphysema. Currently getting bi-weekly infusions of Prolastin®, this incredible lady is still waiting for a cure!

New Staff Members

The AlphaNet family welcomes **Roger Bray** as our newest Coordinator. Diagnosed in 1997, Roger lives in Lexington, KY with his wife Virginia. He will provide service to Alphas in KY and IN.

Welcome also to **Julian Sardinias**, who recently graduated the University of Miami and joined AlphaNet as our accountant.

Healthcare Costs Top List of Americans' Personal Worries

The ability to pay for healthcare is the top personal concern for Americans, according to a poll conducted by the Kaiser Family Foundation. The "Health Security Watch" asks Americans a series of questions designed to measure how worried they are about their own healthcare needs over the next six months. In the latest survey conducted in April, 65 percent of respondents said that they are either very worried or somewhat worried that that their healthcare costs will increase. In addition, 34 percent of respondents believe that their health plans will be more concerned about saving money than about providing them the best treatment. When asked how their concern over healthcare costs compares with other personal worries, respondents indicated that they are more worried about healthcare costs than about paying their rent or mortgage (17%), losing money in the stock market (16%), being a victim of terrorist attack (14%), or losing their job (13%).

Alpha-1 Foundation Tries Out United Way and Combined Federal Campaigns

By Robert V. Callahan, Vice President for Development, Alpha-1 Foundation

Two of the largest charitable campaigns in the nation will be targeted by the Alpha-1 Foundation this year, for the first time. The United Way involves companies all over the nation in a two-month drive to secure payroll-deduction pledges from employees of participating companies. The Combined Federal Campaign does the same thing amongst federal employees. The two efforts raise hundreds of millions of dollars.

The Alpha-1 Foundation will be seeking to mobilize the Alpha-1 community to tap into their network of close friends and family members. The plan is to ask folks who normally contribute through these campaigns to simply designate the Alpha-1 Foundation as their charitable choice. If you would like to learn more about this effort, or if you would like to help, please call Angela McBride at (888) 825-7421 extension 233. Or you can read about the program on the Foundation web site, www.alphaone.org.

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