

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

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THE

AlphaNetter

The Bayer DirectSM Program

AlphaNet is proud to continue its service to the Alpha community as a partner in the Bayer DirectSM Program. This new program has been well received by the majority of Alphas who understand the reasons for its origin. Although the short period of time between the program's announcement and its effective date caused some confusion, many of the problem issues that emerged during the transition have been addressed and resolved, while others near resolution.

Please take a few minutes to read this issue and familiarize yourself with the program and with your AlphaNet Coordinator. Feel free to contact your Coordinator at the phone number indicated in the left column of this page, and ask any questions you have regarding the program and your individual situation. If we don't know the answer to your question, we will do our best to get it for you.

The Bayer DirectSM Team

The Bayer DirectSM team, comprised of employees from Bayer Corporation, Express Scripts and AlphaNet, brings together dedicated professionals who are able to meet the needs of the Alpha community. Bayer is the manufacturer and, as of November 1, 1999, the exclusive distributor of Prolastin[®]. Express Scripts is the nation's largest independent full-service pharmacy benefit manager with expertise in specialty distribution and infusion services. AlphaNet is a not-for-profit organization dedicated to providing comprehensive services to Alphas. The Bayer DirectSM team will be able to provide more equitable treatment to all Alphas enrolled in the program.

- Bayer Corporation is the sole manufacturer of Prolastin[®].
- Express Scripts (Specialty Distribution Services Division) performs insurance verification, maintains medical record documentation, communicates with patient physicians, develops nursing care plans and arranges home infusion, monitors quality assurance, ships Prolastin[®] and other medical supplies, and bills and collects payments from patients and insurance carriers.
- AlphaNet's Coordinators, themselves alpha,-antitrypsin deficient individuals, are available through a 24-hour, 7-day a week help-line service. The help-line service offers referrals as well as counseling and educational support to subscribers, their families and physicians. AlphaNet has consulted with Express Scripts and Bayer Corporation to develop a comprehensive ancillary supply package for use during infusions.

AlphaNet's Role as a Service Provider for Bayer DirectSM

AlphaNet Coordinators will be available 24 hours a day, seven days a week for help-line services to include emergency referrals, counseling, and educational support to Bayer DirectSM subscribers, their families and their physicians. As appropriate, AlphaNet assists in the transition of established Prolastin[®] users to the Special Distribution Services (SDS) at Express Scripts. Coordinators also help newly diagnosed Alphas understand the program and aid them in the enrollment process. AlphaNet's history of "Alphas serving Alphas" will continue on a grander scale with fourteen additional Alphas recently brought aboard to provide the support and service for this new endeavor.

Specific Services:

- AlphaNet will conduct educational intake sessions for newly diagnosed Alphas and other Bayer DirectSM subscribers.
- AlphaNet Coordinators and Nursing Staff will support and consult with physicians, infusion nurses and Bayer Sales Representatives, as needed, to provide disease and treatment information.

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Introducing AlphaNet's Coordinators

AlphaNet Coordinators will be available 7 days a week to provide information and support both during and after the transition to Bayer DirectSM.

Gayle L. Allison (ext. 424)

Georgia, South Carolina, North Carolina, Virginia, West Virginia

Gayle lives in Hurricane, West Virginia with her son and daughter. She is the West Virginia local Alpha support group leader and editor of the AWARE newsletter. She was a board member of the Alpha 1 Association and is currently a coordinator for their support groups. She was diagnosed in January 1998 and previously worked in planning and development for a public utility company for 18 years.

Patti A. Brown (ext. 425)

East Texas

Patti lives in Grand Prairie, Texas. She has been an active member of the North Texas Alpha₁ support group for four years and publishes a regional newsletter, the Lone Star Alpha, distributed to 153 Alphas in Texas, Oklahoma and Louisiana. She was diagnosed in 1993.

Richard A. Bueker (ext. 426)

Kansas, Iowa, Missouri

Dick was diagnosed by his primary care physician in 1989, has two sons and lives with his wife in Kansas City, Missouri. He is the president/coordinator of the Alpha₁ Association, Midwest Chapter. He was a teacher/administrator for 31 years and enjoys traveling and fishing.

Victoria S. Cameron (ext. 427)

Maine, New Hampshire, Vermont

Vickie has three children, eight grandchildren and lives with her husband in West Topsham, Vermont. She was diagnosed this past January. She worked at Dartmouth College for ten years and enjoys knitting and other crafts.

Dorothea S. Craft (ext. 428)

Colorado

Dottie lives in Lakewood, Colorado. She was diagnosed in 1984 and lost her only sister to AAT deficiency in 1996. Three of her four brothers are MZ carriers. She is an advocate for early testing of family members to start proactively practicing a healthy lifestyle to prevent further pro-



Standing (left to right) Darrell Nall, Judy Rose, Joyce Finch, Patti Brown, Mary Pierce, Kay Kinsel, Pat MacInnis, Ken Minnigerode, Janis Berend, MSN, CNP, Cathy Valenti, Kathy Haduck, Terry Young, General Manager, Dottie Craft, Bob Barrett, CEO. Seated (left to right) John Walsh, Board Chairman, Marta Strock, Kathy McKay, RN, Fred Walsh, Gayle Allison, Shirley St.Cyr, LPN, Victoria Cameron. (Not pictured are Dick Bueker and R. Bruce Moody, MD.)

gression of the disorder. She worked as a social work supervisor, youth center counselor and prison counselor.

M. Joyce Finch (ext. 210)

Michigan, Indiana

Joyce was diagnosed in 1992 and is involved with the West Michigan local Alpha support group and the Michigan Resource Group in Ann Arbor. She loves talking to Alphas and has been an AlphaNet coordinator for two years. She has three children, three grandsons, one granddaughter and lives with her husband in Greenville, Michigan, where she enjoys camping and sewing.

Kathleen A. Haduck (ext. 429)

Pennsylvania, Maryland, Delaware

Kathy lives with her husband in Blandburg, Pennsylvania. She was diagnosed in March 1995 after her sister was diagnosed. She has two sons and three grandchildren.

Kathryn R. Kinsel (ext. 421)

North Dakota, South Dakota, Nebraska, Washington, Oregon, Montana, Wyoming

Kay was diagnosed in November 1994 and started a local Alpha support group in Wyoming that expanded to Northern Colorado. Two of her three siblings have also been diagnosed with AAT deficiency. She was formerly employed as an office manager/personnel director for a not-for-

profit research and development organization. She has four children, eight grandchildren and lives with her husband in Laramie, Wyoming.

Patricia E. MacInnes (ext. 430)

New York, New Jersey

Pat lives with her husband in Monroe, New York. She was diagnosed in 1991 and is a member of the New Jersey AlphaOne Support Group. She has a daughter and a son and enjoys swimming, walking and reading.

Kenneth L. Minnigerode (ext. 431)

Illinois, Arkansas, Louisiana, Mississippi, Alabama, Tennessee

Ken lives with his wife in Fairview Heights, Illinois where he was the assistant vice president of Chase Manhattan Mortgage. He has been in the mortgage business for the last 15 years. He was diagnosed by a young internist fresh out of medical school in 1995 and has four daughters and one son. Ken still likes to take his boat out on weekends and fish.

Darrell J. Nall (ext. 433)

Wisconsin

Darrell was diagnosed in 1996 and lives with his wife in Bloomington, Illinois. He was employed in the agriculture equipment sales field for 23 years prior to joining AlphaNet. He has two daughters and enjoys playing golf.

Mary K. Pierce (ext. 216)
Ohio, Kentucky, Connecticut,
Washington, D.C.

Mary lives with her husband and son in St. Joseph, Michigan. She was diagnosed in 1987 and received a double lung transplant in 1993. Since her transplant, she has won several medals for Team Alpha in cycling at the U.S. and World Transplant Games. She is an inspiration for all Alphas to be physically fit and to stay healthy. She is a Certified Public Accountant and worked as an insurance executive with a Fortune 250 company.

Judy K. Rose (ext. 422)
Nevada, Arizona, Utah, New Mexico,
Oklahoma, West Texas

Judy lives in Tucson, Arizona. She was finally diagnosed in April 1997 after a 10-year search. She is secretary of the Alphazones Chapter and has helped launch and coordinate the Alpha1 Association's mentoring program. She has two grown children and was previously employed as a business manager. Her passion is helping newly diagnosed Alphas understand their disorder and increase their quality of life.

Shirley R. St. Cyr, LPN (ext. 213)
Minnesota

Shirley was diagnosed in January 1993, then two of her siblings were diagnosed within three months. She is a member of her local Alpha support group and Team Alpha1. She received the Robert Reinhardt Humanitarian of the Year Award in 1998 by the American Lung Association. She lives with her husband and five children in Waukegan, Illinois. While waiting for a lung transplant, she enjoys gardening and helping other Alphas.

Marta C. Strock (ext. 219)
Florida, Virgin Islands, Puerto Rico

Marta lives in Sarasota, Florida, has been an Alpha coordinator for 3 years and facilitates the Sun Coast local Alpha support group. She was diagnosed in 1993 and her brother, who received a single lung transplant, was diagnosed in 1992. She loves the outdoors and talking to newly diagnosed Alphas.

Catherine A. Valenti (ext. 236)
California, Idaho, Hawaii, Alaska

Cathy was diagnosed in 1995 and worked as a computer technician for a local hospital. She is the Idaho Alpha₁ support group coordinator, publishes a newsletter for Alphas and regional doctors, and has participated in several clinical studies for AAT deficiency. She encouraged

her Governor to declare May 1999 Idaho Alpha₁ Awareness Month and her Senator to declare May 1999 National Alpha₁ Awareness Month. She has two children and lives with her husband in Meridian, Idaho.

Fred C. Walsh (ext. 208)
Massachusetts, Rhode Island

Fred lives with his wife and two daughters in Duxbury, Massachusetts. He is a former high school teacher and building contractor. He was diagnosed in 1989 and then his twin brother was tested and diagnosed. He has a masters degree in counseling and has been employed by AlphaNet for four years.

General Manager

Terry L. Young (ext. 514)
Terry was diagnosed in 1992 and has been working with AlphaNet since its inception in 1995. He helped organize and establish the first chapter of the Alpha1 Association and served on the Board of Directors of the Florida Chapter until 1999. He organized and coordinates the Northeast Florida Alpha₁ support group. He has two sons, a granddaughter and lives with his wife in St. Augustine, Florida.

Accounting and Human Resources Manager

Diana J. Patterson (ext. 243)
Diana is currently in the process of moving from Colfax Louisiana to Miami with her husband, Jim. She has two sons ages 20 and 24. She was diagnosed in August 1988. She worked as a Finance Director for the School Board in Colfax and she organized and set up the Louisiana State support group. She is very happy to be in Miami and working with and for Alphas.

Director of Nursing

Janis G. Berend, MSN, CNP (ext. 220)
Janis has been in the nursing field for over 25 years. She has worked with Dr. Robert Sandhaus and Alpha₁ individuals for the last 10 years. Her present position is at the Alpha One Clinic, Clinical Research Center, National Jewish Center in Denver. She has been the Director of Nursing for AlphaNet for the past 4 years. She lives in Brighton, Colorado with her husband.

Kathleen M. McKay, RN, BSN (ext. 212)
Nursing Coordinator

Kathy has specialized in the care of Alphas since 1991. She is active in coordinating nursing services for Alpha-

Netters as well as providing training for their nurses. She has participated in coordination of clinical trial studies for AAT deficiency, has presented at national conferences and has been active with the local Alpha support group. She moved from Maine to Pennsylvania, where she lives with her husband and two sons.

R. Bruce Moody, M.D. (877-227-8020)
Dr. Bruce Moody is a former member of the A1A Board of Directors and continues to play an active role within the Alpha community. A retired physician, Dr. Moody assists other Alphas and their physicians understanding Alpha₁ and its therapies. Dr. Moody enjoys golf and lives in Mesquite, Nevada with his wife Laine.

— continued, AlphaNet's Role

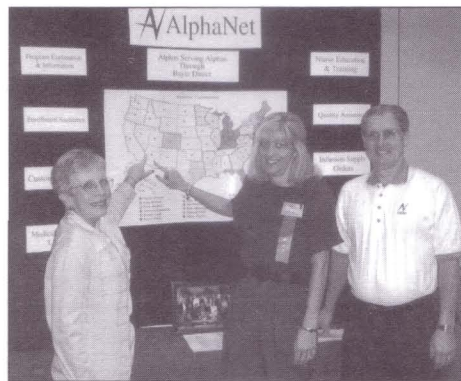
- AlphaNet Coordinators will assist Bayer DirectSM subscribers with infusion supply inventory and ordering.
- AlphaNet will conduct regular meetings with Express Scripts and Bayer to coordinate services and provide educational training.
- AlphaNet will provide information and guidance for understanding Medicare and Medicaid and how they affect therapy. Those Alphas unable to pay co-insurance will be advised concerning availability of alternative assistance.
- AlphaNet will provide a quarterly newsletter to Bayer DirectSM subscribers.
- AlphaNet will facilitate the transition of new subscribers between their former Prolastin[®] provider and Express Scripts.
- AlphaNet will provide a voice for Alpha subscribers, and support insurance and nursing agency negotiations.
- If requested, AlphaNet Coordinators will coordinate non-pharmaceutical therapies and other medical services.
- AlphaNet Nursing Staff will work with Express Scripts and be available for identification, recruitment, training and quality assurance of infusion nurses.

In addition, AlphaNet will support all efforts that promote awareness, detection, and education.

AlphaNet will also develop, and make available to Bayer DirectSM subscribers and their physicians, a comprehensive Alpha₁-Antitrypsin Deficiency Disease Management Program. This will include care modules for nutrition, medication review, standardized infusion protocol and exercise recommendations.

Netter Notes

- ◆ In May 1999, AlphaNet Coordinator Mary Pierce received an Honorary Tribute Award — WGA Special Salute — from the Women's Community Association of Berrien County, MI, for her determination, optimism, and joyful spirit.
- ◆ On September 12 and 13, AlphaNetters Joe Reidy, Alice Dunkley, Sally Everett and AlphaNet Coordinator Fred Walsh attended the 2-day workshop on Alpha, screening and detection sponsored by the Alpha One Foundation.
- ◆ On September 17, in spite of Hurricane Floyd, the ALA 15th Annual Autumn Escape Bike Trek from Plymouth to Provincetown, MA got underway with a record turnout of riders. There was a strong show of support with 80 people representing Team Alpha. AlphaNet coordinators, Mary Pierce, Shirley St. Cyr, Fred Walsh, Kathy McKay, family, extended family and friends were on hand for the three-day event. Also in attendance at the lobster dinner on Saturday night were AlphaNetters Julie Bakula with her daughter, Susie, and Janet Reardon with her husband, Jack. Thanks to Bayer Pharmaceutical for sponsoring Team Alpha riders again this year.
- ◆ More than 50 influenza vaccinations were administered free of charge to alphas, family members and friends at the SERAEC meeting in Birmingham, AL, October 17 and 18, 1999 and the Alphazonies Conference in Phoenix, AZ, November 13, 1999. AlphaNet is



Carolyn Aspergren, Alphazonies Chapter President, with Judy Rose, AlphaNet Coordinator and Alphazonies Secretary, and Terry Young, AlphaNet General Manager at the AlphaNet booth in Phoenix, AZ.

proud of its continuing sponsorship of this flu prevention program.

- ◆ Kudos to AlphaNetter Lynda Lindsey for all her work on the SERAEC auction. The auction raised over \$1,800 for the Peter Smith Scholarship Fund.
- ◆ Special thanks to Elizabeth Gaddus, AlphaNetter from Cleveland Ohio for the wonderful job she did designing the beautiful 1999 Christmas cards. Elizabeth is a graphic designer and calligrapher, and has worked on the holiday cards for the past two years.
- ◆ On January 25, 2000 Pamela Sims and AlphaNet Coordinator Judy Rose spoke at the national meeting of Bayer Corporation's pharmaceutical sales representatives in Sanibel, Florida. They discussed alpha₁-antitrypsin deficiency and the effect of ProLastin[®] therapy on their daily activities.

Events Calendar

- ◆ The Texas Alpha Research Conference 2000 will be held on March 4 at the DoubleTree Hotel in Austin, TX. The registration fee is \$20. For more information or to register, call Laurie Lackland at 903-877-7840.
- ◆ The Alpha 1 Association Annual Conference will be held in Charlotte, NC from April 29 through May 1, 2000.

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 241.

Patient Notification System

For information regarding the most recent regulatory actions or to enroll in the confidential Patient Notification System for the Plasma Products Industry, call

1-888-UPDATE-U

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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