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Editorial Office:

AlphaNet, Inc.
2937 SW 27th Avenue, Suite 302
Miami, Florida 33133

How to Contact AlphaNet:

Phone: 1-800-577-2638
Fax: 1-305-442-1803
Website: <http://www.AlphaNet.org>.

Terry Young: Ext. 514

Director of Coordinators
E-mail: tlyoung@alphanet.org
Phone: 1-800-278-1804
Fax: 1-904-264-9495

Joyce Finch: Ext. 210

AlphaNet Coordinator
E-mail: jfinch@alphanet.org
Phone: 1-888-225-9012
Fax: 1-616-754-2816

Marta Strock: Ext. 219

AlphaNet Coordinator
E-mail: mstrock@alphanet.org
Phone: 1-888-399.0443
Fax: 1-941-377-0688

Fred Walsh: Ext. 208

AlphaNet Coordinator
E-mail: fcwalsh@alphanet.org
Phone: 1-800-791-3194
Fax: 1-781-837-5430

Robert C. Barrett: Ext. 229

Chief Executive Officer
E-mail: rcbarrett@alphanet.org
Phone: 1-800-577-2638
Fax: 1-305-442-1803

Janis Berend: Ext. 220

Director of Nursing
E-mail: jberend@alphanet.org
Phone: 1-303-398-1858
Fax: 1-303-270-2216

Mirtha Vazquez: Ext. 243

Accounts Manager
E-mail: mvazquez@alphanet.org
Phone: 1-800-577-2638
Fax: 1-305-442-1803

THE

AlphaNetter

Being Part of the Solution

— by Terry Young, Director of AlphaNet Coordinators

In October 1998, Dr. Mark L. Brantly relocated from the National Institutes of Health in Bethesda, Maryland to the University of Florida at Gainesville to direct the Alpha One Research Program. The research center is made possible in large part by the Alpha One Foundation. I was looking forward to being evaluated by one of the best "Alpha docs" in the country.

The University of Florida is a two-hour drive from my home. I was accompanied there by two of my friends from Michigan, Ed and Joyce Finch; Joyce is an AlphaNet Coordinator. After having a chest x-ray and a pulmonary function test, I had a lengthy review of the test results with Dr. Brantly. I always take a list of questions and concerns when seeing any physician. Dr. Brantly answered all my questions clearly, directly and in detail. There is a calming confidence that comes with having my medical records reviewed by a doctor who has so much understanding and experience with A1AD.

After my appointment, Dr. Brantly invited Ed, Joyce and me to tour the Alpha One Laboratory. I was particularly impressed with the nephelometer, a machine that separates and identifies the amount of AAT in blood samples. We were introduced to the lab's Senior Technician, Chris Tobias, and lab technician DJ Salzano, as well as Gwen Moen, the Coordinator of the Alpha One Clinical Research Program.

The visit was an enlightening experience. I feel very proud to be participating in the Registry. I recommend that all alphas of all phenotypes, sign up for the Registry in the Alpha One Research Network. Everyone involved will learn more about alpha₁-antitrypsin deficiency as it pertains to them while being part of research that helps all alphas. Be a part of the solution!



Senior Laboratory Technician, Chris Tobias, working in the phenotyping lab

Alpha One Research Program at the University of Florida

— by Symma Finn, Research Administration, Alpha One Foundation

Patients who visit the University of Florida Alpha One Research Program are either invited to participate in a clinical trial, or are visiting the Pulmonary Clinic for specialized outpatient care from Dr. Mark L. Brantly. Following any previously scheduled tests — chest x-ray, CT scan or Pulmonary Function Test (PFT) — patients proceed to the Physician's Diagnostic Clinic and are given a preliminary physical exam by nurses specifically assigned for alpha patients. Afterward, they meet with Gwen Moen, Nurse Practitioner for the Alpha One Research Program, who spends about an hour getting a detailed medical history and giving a complete physical exam. She explains Dr. Brantly's work and the Alpha One Research Program in detail, answering questions and providing follow-up reading material about the Alpha One Foundation along with information about enrollment in the Registry. She also administers a lengthy questionnaire similar to that used by NIH in their longitudinal study, and provides the patient with information about nutrition and exercise.

The patient then meets with Dr. Brantly. After he has been briefed by Gwen Moen on medical history and test results, Dr. Brantly examines the patient himself, focusing on the lungs, — continued on page 3, col. 1

Making Your Home Allergy-Safe

— by Joyce Finch, AlphaNet Coordinator

One way to find relief from your allergies is to try to avoid the things that aggravate them. If you can make your home, especially your bedroom, allergen-free (or at least reduce allergens), and take other steps to avoid allergens in your daily activities, you can live with your allergies much more easily.

Here are some tips to help you reduce seasonal allergies in your home:

1. Install an air filter in your forced air heating and/or cooling system.
2. Change your clothes and shower when you come in from the outdoors. (Pollen sticks to your hair and clothes and continued exposure can aggravate your symptoms.)
3. Leave your shoes at the door. (Pollen and mold comes in on your shoes and can continue to aggravate your symptoms.)
4. Keep pets out of the bedroom and especially off the bed. (In addition to dander and dust mites, pets carry pollen grains in from outdoors.)
5. Wash all bed linens, including pillows, in hot water — at least 130 degrees F. — to remove dust mites.
6. Use washable window treatments and wash them often.
7. Avoid carpeting in the bedroom and throughout the house, especially deep pile carpets.
8. Use a HEPA filter on your vacuum cleaner.
9. Keep the windows closed and use an air conditioner.
10. Keep the surfaces in your bedroom uncluttered; store books, CDs, and stuffed animals in other parts of the house.
11. Clean your home and car air conditioners at the beginning of each allergy season.
12. If you don't have an air conditioner, a furnace filter placed in an open window can filter allergens.
13. For forced air heating or air conditioning systems, you can keep seasonal allergens out of your room by putting a double layer of cheese cloth over the vents.
14. Keep windows closed at night and car windows closed while traveling.
15. Encase mattresses, pillows and box springs in airtight or allergen-proof casings. Use comforters and pillows made of synthetic fiber rather than down, kapok or cotton. Replace pillows every two to three years.
16. Have a non-allergenic person in your household bathe your pets weekly and brush them often.
17. Have a non-allergenic person in your household dust and vacuum all surfaces.
18. Keep activity to a minimum between 5AM and 10AM when pollen is usually released into the air.
19. Avoid raking leaves or mowing lawns, which stirs up mold.
20. For mold allergies, use a dehumidifier in damp areas and do not sleep in basement-level areas.
21. Avoid having indoor plants; mold grows in wet soil.

Update On the Prolastin Shortage

The following is a copy of the June 30th letter from Bayer Pharmaceutical Division concerning the status of the Prolastin shortage and the increase of al-

locations from 60% to 80%. As of August 1, 1999, the allocation remains at 80% with no additional information available as to when the situation might change.



Pharmaceutical
Division

Bayer Corporation
400 Morgan Lane
West Haven, CT 06516-4175

June 30, 1999

Dear Bayer Customer:

Effective July 1, 1999, we will be increasing your allocation of Prolastin® (alpha 1 proteinase inhibitor {human}) from 60% to 80% of your average monthly purchases during the period of October - December 1997. This allocation system was originally initiated in January 1998 in order to distribute available product in the most equitable fashion.

We at Bayer continue to recognize our responsibility to the patients who depend on Prolastin®. We continue to release product from both our Clayton, NC and Berkeley, CA facilities. Additionally, we are expediting packaging and distribution of Prolastin® lots currently in process and are working closely with the FDA to speed product releases. Bayer will continue to monitor supplies and adjust the allocation accordingly. As you know, unforeseen problems can also affect the scheduled releases of our products.

It is important to note that the current allocation program is in no way intended to guide dosing considerations for patients. Patients with questions regarding dosage or any treatment concerns should consult with their physicians.

A Bayer Clinical Communications Specialist is available to answer clinical questions regarding Prolastin® by calling 1-800-288-8371.

If you have any questions concerning your allocation, please contact our Customer Service Department at 1-800-243-4153.

Thank you for your understanding and cooperation during this difficult period.

Sincerely,

Maura S. Fashjian
Assistant Product Manager

Joe Zuraw
Product Manager

— continued, RESEARCH PROGRAM

and tells the patient what he thinks should happen next. This could be to continue to see their own pulmonologist, return for follow-up care with Dr. Brantly, or participate in a clinical trial, if eligible.

The Alpha One Research Program and Professorship at the University of Florida College of Medicine is the first academic research program of its kind devoted to the study of alpha₁-antitrypsin deficiency. The Program allows researchers in related areas to coordinate alpha₁ research within one setting, and maximize shared use of state-of-the-art equipment, laboratory facilities and personnel. Researchers in the gene therapy laboratories, lung transplantation units and those investigating both conventional and novel forms of therapy for alpha₁ are able to coordinate their efforts, share expertise and utilize the specialized equipment in the Alpha One Research Program laboratories for both research studies and clinical practice relating to alpha₁-antitrypsin deficiency.

NURSE'S CORNER

— by Janis Berend, MSN CNP,
AlphaNet Director of Nurses

Here are a few questions I usually ask alpha₁ patients I see at the National Jewish Medical Center in Denver, Colorado:

1. Are you smoking? If so, stop. Are you exposed to anyone who is smoking?
2. Do you have small children who expose you to infections? Are you conscientious about hand washing and avoiding hugs and kisses from sick family and friends?
3. Do you have a job that exposes you to irritants, chemicals, etc.?
4. Do you know about your medications, why you take them, how to use them effectively, and any possible side effects?
5. Do you have good technique with inhalers; are you using a spacer and do you clean your spacer? If you use a nebulizer, is it cleaned properly?
6. Have you had a yearly flu vaccination as well as pneumonia vaccination every 5-6 years?
7. Have you ever used a PEAK Flow meter? Would this help you in monitoring your condition and get you to your doctor before you end up in the ER? (You can work with your doctor to set up a plan of things to do if your peak flow drops and does not improve after using a bronchodilator.)

The Reidy Report:

The Alpha 1 National Conference, 1999

— by Joe Reidy, AlphaNetter

Fred Walsh called and asked me to do the impossible: write a short article for *The AlphaNetter* about my experiences at the Alpha 1 Conference in Overland Park, Kansas. And he wanted it done yesterday! I selected one of many meeting highlights as my topic.

On Saturday, May 15th, Dr. Clifford Steer of the University of Minnesota presented one of the most encouraging talks I have ever heard at a National Conference. It was fairly technical and I did not understand all of his presentation. Basically, Dr. Steer is studying the "Repair of Genetic Diseases of the Liver with Single Point Mutations." He mentioned a few types of genetic mutations such as Hemophilia-B, Crigler-Najjar syndrome and Alpha₁-Antitrypsin Deficiency. I believe Dr.



Karen Fraser, Terry Young, Joe Reidy and Joe Zuraw (Product Manager from Bayer) at the AlphaNet booth.

Steers chose to work with Hemophilia-B because animal models are readily available. He chose not to initially concentrate on A1AD because of the complications inherently found by it being destructive to both the liver and lungs.

To summarize as best I can, Dr. Steer said he was able to change the cells in the livers of rats and dogs such that they would produce the deficient protein, Factor IX. He claimed he could cause change to about 40% of the liver cells' DNA with a one time infusion. The changes were permanent in that when the "corrected" cell divided, as they naturally do, both daughter cells had the corrected DNA. The dogs who had the infusions produced enough factor IX such that their blood clotted, albeit slower than normal. He expected to be working with human subjects within less than a year.

He stated that, as it applied to A1AD, he would convert PiZZ individuals to PiMZs. I did not understand why he could not make PiMZs into PiMMs. It sounded to me that a one-time infusion would increase the AAT levels in our blood from 15% of normal to almost 30% of normal. Might this just be enough to keep asymptomatic Alphas asymptomatic?

After the lecture I asked various Alpha docs for their impressions. The ones who attended the lecture were quite upbeat. In fact, one said, "I have always been rather skeptical of gene therapy, but this one sounds like it may be the real thing." It was pointed out that no one was aware of any published reports and his claims have not been duplicated independently. Be that as it may, the report was exciting and I hope we hear how Dr. Steers experiments pan out.

PS. If anyone would like a copy of the ten-page report I prepared for my local support group, I would be happy to send it via E-mail or U.S. Postal Service.

E-mail:ReidyJoe@AOL.COM

8. Are you exercising? Have you been to a rehab program to learn proper exercising technique? Do you need to use oxygen while exercising? Do you need information on conserving your energy?
9. Are you working well with your doctor to get treatment for infections and do you know when to *call* the doctor vs when you need to be seen?
10. Do you need an EpiPen to treat anaphylaxis and know how to use it? And after use, call 911.
11. Are you compliant with oxygen? You cannot tell whether you need oxygen by how you feel; you need to be checked at rest and with activity. The oxygen company can do this or it needs to be checked routinely by your physician.
12. Do you have sleep problems, snoring, thrashing in bed, daytime somnolence, morning headaches? This may suggest sleep apnea and require a sleep study for assessment.

We at AlphaNet are available to you and your nurse. When you have problems, we can help you find the resources to solve them. Please feel free to call me directly so I can facilitate getting the answers you need.

Phone: 1 800 577-2638 ext 220

Leave a message and a phone number. I will receive your page and I will return your call.

Halfway Up The Stairs

— by Elizabeth Gadus

It is only I and other few
Who can not complete
With our feet
What our lungs refuse to do.

And so
We stop halfway up the stair,
And notice those things
Others wouldn't dare.

Special molding aside the step
Crayon marks where the children crept.
The coffee stain from long ago
And wall scuffs that we hope don't show.

The way the ceiling takes a tilt,
How awkwardly the hallway's built,
The painter's missed a spot right there,
The wood's replaced inside the stair.

With every step that I must stop
And continue in slow pace,
I find a spot not seen before
That occupies my space.

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.

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

Netter Notes

◆ On April 24, once again, Bentley, my friend Kathy (first time for this ride), and I headed up the Withlacoochee State Trail in Florida for another American Lung Association's bike ride. Once



Marta Strock

again, I was greeted with a warm welcome by Anne Black and Vicki Stauffer, the ride's coordinators. Once again, I enjoyed the ride through the woods along the eight-foot wide paved trail. And once again, I canoed down the Withlacoochee River the next day. I plan to return next year!

◆ At the National Conference in Overland Park, Kansas, May 14-17, AlphaNetter Shirley St. Cyr and Team Alpha Captain Mary Pierce received the "Overcoming the Odds" award for their participation in the American Lung Association's "Big Ride" last summer.



AlphaNetters Terry Young, Fred Walsh and Sandy Lindsey

◆ On June 11, in Miami, Florida AlphaNetters Terry Young, Fred Walsh and Sandy Lindsey attended "Lunch With the Champions", a fund-raising event

sponsored by the Alpha One Foundation. Among the more than 400 in attendance were New York Yankees' Manager, Joe Torre, Florida Marlins' Manager, John Boles, and a number of major league baseball players.

◆ AlphaNetter Tom McLaughlin of Hellertown Pennsylvania, can be seen in the newly released Bruce Willis film, *The Sixth Sense*. Look for him in the last scene of the film. He is the father of the bride on a videotape of his daughter's wedding which is running in the background of that scene. Tom has done many voice commercials but this is his first shot at the "big time."

◆ AlphaNetter Julie Bakula's successful recovery from lung transplantation has been complicated by a fall in which she broke her back. Her rehab program is producing great results and she should be home again soon.

◆ The American Lung Association's 15th Anniversary Autumn Escape Bike Trek from Plymouth Massachusetts to Provincetown, scheduled for September 17-19, is anticipating a team of 50 plus riders from eight states representing Team Alpha. Call Mary Pierce at (888) 825-7421 ext 216 if you're interested in joining the ride. Team Alpha is sponsored by Bayer Corporation.

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

The AlphaNetter

AlphaNet, Inc.
2937 SW 27th Avenue, Suite 302
Miami, Florida 33133

