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THE AlphaNetter

Prolastin Supply Update

By Dr. Sandy Sandhaus

As I discussed in the last issue of *The AlphaNetter*, with the success of efforts to identify new individuals with Alpha-1 and the scheduled maintenance of the Bayer production facilities, it is anticipated that there will be a strain on the supply of Prolastin®.

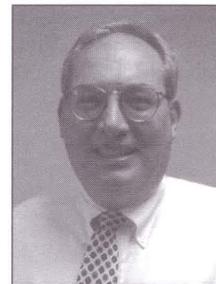
Since the start of the Bayer Direct program in November 1999, there has not been a significant shortage or interruption in the distribution of Prolastin. We have made it through the dangerous winter months with full supplies available.

This issue of *The AlphaNetter* includes a letter from Bayer Direct defining the allocation plans for available Prolastin, should an interruption occur. Shipping schedules could change with little advance notice as Prolastin is released and, as Bayer Direct tries to expedite deliveries once drug becomes available, shipping dates may change quickly. When shortages occur, great flexibility and consideration will be required from all individuals receiving Prolastin, as the Bayer Direct program continues to provide equal access to the entire patient community.

Any shortage at this point will affect the entire community. Please remember that there are many important components to the treatment of the lung disease associated with Alpha-1, in addition to Prolastin therapy. These include the routine use of bronchodilator medications as indicated (inhalers, pills, nebulizers), avoidance of infections (life-style, flu shots, pneumonia vaccine), rapid treatment of infections should they occur, pulmonary rehabilitation, and avoidance of cigarette and other tobacco smoke as well as occupational/environmental exposures to dust and fumes. Please review the statement of the Medical and Scientific Advisory Committee of the Alpha One Foundation which can be found on the AlphaNet and Alpha One Foundation websites (www.alphanet.org or www.alphaone.org).

If a supply interruption occurs and you have "stockpiled" a one or two week supply of Prolastin, it is recommended that you use this saved Prolastin only if you get a lung infection. Remember to check the expiration dates of your "stockpiled" Prolastin and replace these vials with newer drug as necessary. Also check that you have the supplies necessary to administer this extra drug should you need it. If your weight has dropped since your last Prolastin prescription was filled, you should check with your physician to see if your prescription should be changed to reflect that lower weight.

We hope that any potential disruptions in Prolastin can be taken in stride by all. We pledge to keep the Alpha-1 community as well informed as possible.



Sandy Sandhaus

Be Your Own Advocate

By Leigh Polli

If you have Alpha-1 and want to be active and feel good, you have to take care of yourself, learn about your disease, learn about the treatments for your disease and DEMAND that you get the care and treatments you need.

Because of the health care system in this country, doctors have very limited time for each patient and HMOs would just as soon not pay for any treatments. So how do you get what you need?

Learn about Alpha-1 and any particular health concerns or issues that relate to its effect on you. The easiest way is to go on the internet. Even a novice, such as myself, is able to gather reams of information by using keywords such as emphysema, COPD, oxygen, etc. Get copies of your medical records from your doctor, including PFT results, ABGs, and other blood work and tests done (including analysis of X-rays, CT scans, quantitative ventilation/perfusion studies, etc.). Then read all of this. A lot of it may seem like Greek if you don't have a medical degree (which I certainly don't),

— continued on page 3, column 1

Alpha One Foundation Registry Announcement

March 10, 2001

Dear Clinical Resource Centers and AlphaNet Coordinators,

New questionnaires for the Alpha One Foundation Registry are available for distribution. Since we have adequate numbers of the new questionnaires we would ask that you destroy old versions. The new questionnaire differs slightly from previous versions.

The most important change is that carriers will now be accepted into the Registry. The Medical and Scientific Advisory Board for the Foundation has decided that sufficient scientific questions remain unanswered on carriers of the Z allele (MZ and SZ individuals) to begin enrollment of these persons in the Registry. With significant numbers of Z carriers in the Registry, targeted research on lung and liver disease in these individuals will improve understanding of Alpha-1 deficiency for both ZZ and carrier populations. We welcome the family members of Pi ZZ individuals.

Minor changes in the remainder of the questions might be noticed. We are inviting participants to provide hard copies of their spirometry that can be followed serially in the Registry. Persons can now self-designate more than one race or ethnicity and an additional reminder to sign the consent form has been added. Current Registry participants who signed consent forms when the Registry was housed at the University of Miami should be invited to update their enrollment with the current questionnaire.

The Medical University of South Carolina maintains a toll free number (1-877-886-2383) that is staffed from 8:30-5:00 Monday to Friday to assist enrollment, help fill out the form, mail additional questionnaires, or discuss questions about the Registry. As always, the Registry is available to serve you should you have an interesting question that can be answered by Registry data.

Sincerely,

Charlie Strange, MD

Director, Alpha One Research Registry



Bayer Direct

Bayer Corporation
3168 Riverport Trade Center Drive
Maryland Heights, MO 63043
Toll Free: 800 305-7881
Fax: 800 985-1170

March 20, 2001

Dear Prolastin[®] Patient:

Bayer DirectSM is committed to ensuring that all Alpha-1 patients have access to Prolastin[®] [Alpha₁-Proteinase Inhibitor (Human)], that the product is distributed equitably, and that the Alpha-1 community is well informed regarding product supply.

The Bayer facility in Clayton, N. C., experienced its annual shutdown beginning Dec. 29, 2000. It ended Feb. 16, 2001. The purpose of the shutdown was to perform facility improvements, general repairs, and preventive maintenance, as part of the ongoing commitment of Bayer to produce high quality products in the safest, most efficient, and state-of-the-art environment possible. The planned improvements addressed observations made by regulatory inspections and incorporated the findings from periodic internal audits. These internal audits, performed by Bayer personnel, are part of Bayer's quality systems to ensure compliance with current good manufacturing practices. The facility is now in full operation.

Every week, new Alpha-1 patients are diagnosed and enrolled in Bayer DirectSM. Since the inception of the Bayer DirectSM program, more than 300 additional patients are now receiving Prolastin[®]. However, Prolastin[®] manufacturing capabilities remain the same. We are approaching a "critical mass" and demand may soon exceed our supply capacity. The recent planned maintenance shutdown at our Clayton facility, combined with this continually increasing call for product, are leading to interruptions in your regular shipments.

We are advising you of these interruptions in the Prolastin[®] supply to enable you to contact your physician and prepare treatment options for the potential impact of these events. Please be assured that we will keep you apprised as the situation changes. Bayer DirectSM will ship all Prolastin[®] as soon as it becomes available by enacting its "Shipping Wheel" process, ensuring a fair and equitable distribution of product.

The adjacent diagram illustrates the Shipping Wheel process.

The wheel enables Bayer DirectSM to distribute Prolastin[®] as follows:

When the supply of Prolastin[®] is depleted, the next patient due for a refill becomes patient number "1."

- Each patient in the Bayer DirectSM program is added sequentially to the wheel based on the date he or she is due for a refill.
- New patients will still be enrolled in the Bayer DirectSM program and added to the end of the wheel.

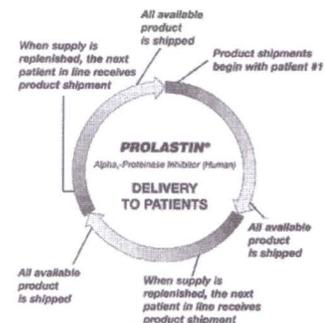
As more Prolastin[®] is released by Bayer Corporation, the Bayer DirectSM program will go to the next patient on the Shipping Wheel and determine how many patients can receive a 28-day supply based on the number of units and assays released. Those patients will be contacted and a shipment will be scheduled. In the instance a release of Prolastin[®] exceeds the current need for all program patients' 28-day supply, the excess will be held at the Bayer DirectSM pharmacy and distributed the following month until it is depleted.

In keeping with our ongoing commitment and agreement with the Alpha-1 community, Bayer DirectSM will continue to ensure Prolastin[®] is distributed equitably and will proactively keep you informed about product availability issues.

Please feel free to contact Bayer Direct at 1-800-305-7881 or your AlphaNet coordinator.

Sincerely,

THE BAYER DIRECTSM TEAM



— continued, *Be Your Own Advocate*

but you will be surprised at how much you can understand. Then make an appointment with your doctor/pulmonologist and ask questions. Write up your questions; be short and concise and don't overdo it. Limit questions to 5-10 or your doctor won't attempt to find the time to respond. Take the questions with you and give a copy to your doctor. The 8 minutes allocated to you will be expanded if you insist on answers (believe me, it works). Based on what I read on the internet, I asked my doctor: (1) why is my hemocrit so high?; (2) okay, then, shouldn't I be on oxygen?; (3) what about pulmonary rehab?; (4) what about different medications?; (5) how about Prolastin infusions?, etc. As a result, over the past several months, (1) I have had a pulmonary rehab class and purchased a pulse oximeter and a treadmill (both of which I use regularly); (2) I got oxygen; (3) ALL of my medications were changed; and (4) I'm on Prolastin. In some cases, I actually took copies of information I had gotten from the internet into my doctor's office.

Be persistent! Nice guys don't win! Be the squeaky wheel. This doesn't mean you have to be obnoxious and unpleasant. But you do have to be firm and insist you get what you need.

Know who will help. Got a denial letter from your insurer? Know what your rights are and push them to the limit. The denial letter should state your appeal rights. You probably have the right to a 72 hour expedited review if your doctor signs the request. Otherwise, most insurance companies have 30 days to review a denial. Gather your facts and write the letter yourself, then ask your doctor to co-sign it.

Sometimes you won't get what you need, but the insurance company won't issue a denial letter. If you are denied a treatment that your doctor has recommended, this is a denial whether they send a denial letter or not. Treat it as a "constructive" denial. Call the insurance company and ask them for a copy of the claim procedures when a denial is made.

These are some of your options:

- If you have a Medicare HMO and appeal a denial of coverage, the insurer is obligated to send a request for review to the Center for Health Dispute Resolution — an agency contracted by the Health Care Financing Administration.
- If the HMO will not provide a denial letter and send a request for review to the Center for Health Dispute Resolution; in California, any denial of coverage entitles the patient to file a complaint with the Department of Corporations, Health

Services Division. Your HMO or insurer should provide information about any similar agency in your state.

- Call your State Department of Insurance and explain the problem; find out what agencies might be of assistance.
- Call your local newspaper, radio and TV stations to see if they will do a story.

In my case, the insurance company didn't deny me the Prolastin; they just didn't provide it, but said they would when they could. My doctor co-signed my appeal and they responded and said they would get it. Then they didn't. Then they withdrew the appeal and said they would get it. They didn't. I arranged through my doctor's office to get the infusion there and procured the Prolastin (shipped directly to my doctor's office) myself. Then I sent the HMO the bills and file complaints with the HCFA and the California State Department of Corporations. In all, I made approximately 15 phone calls, sent 5 faxes, and wrote approximately 5 letters and filed two formal complaints. I did not let up. They reimbursed all the bills and are now paying for the Prolastin infusions in my doctor's office on a weekly basis.

Don't leave your health and happiness in someone else's hands. Educate yourself on what you need and then demand that you get it.

New Coordinators

AlphaNet is pleased to announce the appointment of seven new Coordinators. Following an intense three week training period, they each assumed full responsibilities for their new areas.

Diana Patterson (ext. 440)

Louisiana, Arkansas, Mississippi, Alabama
As most of you know, Diana has worked with AlphaNet previously, in the Miami office, as Accounting and Human Resources Manager. She is a Certified Public Accountant and has worked as Finance Director for the School Board in Colfax, LA prior to retiring last year. She was diagnosed in 1988 and has been actively involved with the Alpha-1 community since then. Diana and her husband Jim have two sons, ages 21 and 24, and live in Colfax, LA.

Terri Seargent (ext. 439)

South Carolina, Georgia, Tennessee
Terri was diagnosed in April 1999 and has been using Prolastin since October 1999. She has been extremely active in the Alpha-1 community this past year. In her previous position, she managed 11 sup-

port positions in an insurance related business. Terri lived in Wilkes-Barre, PA, where she worked for 6+ years with the Boy Scouts of America. For the past 4 years Terri and her husband Harry have lived in Wilmington, NC. They have two sons, age 22 and 23.

Amber Beligni (ext. 441)

Nevada, Washington, Oregon, Idaho

Amber was diagnosed in 1999 and lives in Nevada with her two boys — Brandon, 16 and Trevor, 10. She is 40 years young and currently engaged to Mike Albanese, a great guy who is very supportive.

Trina Stephenson (ext. 443)

Information Manager

Trina was diagnosed in July, 2000 and lives with her husband in the Zuni Mountains of western NM. Previously, she was a librarian for several law firms in VT and also at a state prison for men in NM. She holds several advanced degrees including an MLS and an MS in environmental studies.

Phil Freeman (ext. 442)

Coordinator at Large

Phil was diagnosed in 1993. He lives in southwest MI with his wife Anne and their 13 year old daughter Hilary, whom they home-school. Phil enjoys, but claims not to be proficient at golfing, gardening and woodworking, and spends a lot of time reading. He is very happy to have the opportunity to be an "Alpha serving Alphas" as part of AlphaNet.

Liz A. Veronda (ext. 445)

Illinois, Indiana

Liz was diagnosed in August of 1998. Prior to AlphaNet she worked in industrial sales for 17 years. She promotes Alpha-1 awareness whenever possible. She lives with her husband and stepsons in Carbon Hill, IL where she enjoys camping, fishing and sewing.

Douglas Turley (ext. 434)

Iowa, Kansas, Missouri

Doug Turley was diagnosed in 1997 and lives in Pittsburg, KS. He has managed a bakery, grocery, restaurant, clothing store and a pharmacy until retiring in 1999. Doug is very happy to be working again helping Alphas. He has a daughter, 19, attending West Virginia University.

"We welcome our new staff members to our AlphaNet family. They will add their commitment to our philosophy of Alphas serving Alphas."

Terry Young

General Manager

Alpha Vacations On Location



John Billington infusing with help from fellow Buckskinner

Alpha John Billington hails from Houston TX. Diagnosed in '97 and on Prolastin since October '99, John doesn't let Alpha-1 get in the way of doing some of the things he loves. He's very involved in the support group, loves to talk with other alphas, and has some very unique interests. One of which is his involvement with the "Texas Association of Buckskinners."

Buckskinners (men and women) meet on a regular basis for a "rendezvous" to reenact the lifestyle that existed in the 1700-1840s. They camp out, wear clothes that are authentic to that historical time, have competitions and reenactments of real events.

John just takes his Prolastin along... In fact, the "cooler" is one of the few mod-

ern articles allowed in — most modern conveniences are strictly forbidden. Others in the camp get a kick out of watching him go through the process of mixing and then accessing his port. He's a big believer in ports and anything that will allow Alphas to be independent and not tied to home. He usually draws quite a crowd. John is very experienced, and of course adheres to all the correct procedures.

Anyone interested in contacting John may do so through his email address: ccbillin@ev1.net

Events Calendar

- ◆ Alpha 1 Association National Conference — Tenth Anniversary Education Conference 2001: A Genetic Odyssey Friday April 27-Sunday April 29, 2001 Sheraton San Marcos, Phoenix, AZ. For more information contact: Alpha 1 Association, 8120 Penn Avenue South, Suite 549 Minneapolis MN 55431. Phone: 800-521-3025; Fax: 952-703-9977; Email: A1NA@alpha1.org
- ◆ The 2nd Annual Alpha-1 Benefit Golf Tournament Saturday, May 26, 2001 Esquire Country Club, Barboursville, WV. For details, call Gayle Allison at 1-877-982-5742
- ◆ The Massachusetts Support Group, supported by the American Lung Association of Massachusetts and Bayer Pharmaceuticals, is hosting the second of a 3-part series on transplant. For more information call Fred Walsh at 1-800-791-3194.

Attention Prolastin® Users

A number of AlphaNet Coordinators have received calls from Alphas concerning the variation in number of boxes sent in their monthly shipment. Please pay attention to the RX sticky labels sent with the order. They should be attached to the plastic bags that the Prolastin boxes are sent in. The labels identify what has been sent and how it should be infused based on your doctor's orders. Given the variation in strength of the boxes sent (assay), the number of boxes may change. For example the 1 gram boxes of Prolastin should be 1000 mgs., but can actually be between 800-1200 mgs. Sometimes half gram boxes are sent to reach the desired dose, if there is a scarcity of 1 gram boxes. Take the time to verify what has been shipped and divide the product up according to dose and frequency. PLEASE check your coolers when they arrive. Probably a good practice is to save the stick-on labels just in case of shipping/dosage discrepancies. (This information is kept at Bayer Direct as well). We realize that those Alphas infused at a clinic, hospital, or doctor's office don't have that luxury. Don't be bashful, know when your product is to arrive and, if you have any questions, ask the pharmacist or person in charge of your infusion what was sent. If you need assistance, call your Coordinator.

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

The AlphaNetter

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Return Service Requested

