

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

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THE

AlphaNetter

Joining a Research Study

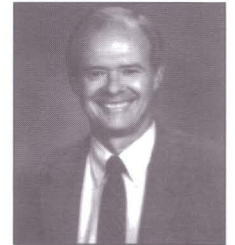
By Tom McLaughlin

Between April 7 and June 30, 2001, I participated in a study sponsored by Bayer Corporation to test "the safety and tolerability of recombinant alpha-1 antitrypsin given by nebulizer to patients with A1AT deficiency." I had tried several times over the last few years to find a study in which I could involve myself, but I either didn't meet the criteria or my pulmonary doctor advised against it after reviewing the guidelines and assessing risk factors.

Obviously, participating in a study like this involves a commitment of time and energy and the acceptance of a certain degree of risk. I had to visit New York City six times during the course of the study, give blood, take numerous PFTs, and keep a daily diary of my experience with the medication.

What I want to emphasize and share with other alphas is the feeling of satisfaction I got from finally being able to give something back to the "Community." It's gratifying to send a check to the Foundation, but getting involved in an effort like this was more personally rewarding to me. I hope, of course, that efforts of all the participants will lead to a new source for an Alpha-1 product, one that may be more effective than infused Prolastin and, more importantly, one that can be produced in unlimited quantities.

I urge all my fellow alphas to keep their ears and eyes open for future Alpha-1 studies. It is essential, however that each alpha's doctor agree they are physically able to handle the commitment and the risks associated with that particular research study. My doctor has taken the time to understand fully the ramifications of each study I've presented to him and advised me accordingly. It worked for me and the experience truly made me feel good.



Tom McLaughlin

The Medical Information Bureau

By Trina F. Stephenson, MLS, MS, Information Manager, AlphaNet

What does the Medical Information Bureau (MIB) do?

Few people have ever heard of the Medical Information Bureau, but there's a good chance that it knows all about you. The MIB's main job is to identify people who falsify their insurance applications. If an insurer knows that you had heart surgery, it will likely report this to the bureau. If you later apply for medical or life insurance but fail to mention the operation, a quick check with the MIB can uncover it. The result is that your application may be declined, or the insurer may insist on a higher premium. Even if an untruth slips through the cracks during the application, the company that writes the policy can later cancel the agreement or even refuse to pay a claim if it can show the policy was issued under false pretenses.

Yes, there is a central medical information bureau, and nearly every time you see a doctor, or submit an insurance claim, the fine print on the forms that you fill out and sign allows them to send information to other doctors and clinics and insurance companies, as well as to the MIB. Over 750 insurance firms use the services of the MIB primarily to obtain information about life insurance and individual health insurance policy applicants. Medical conditions are reported using one or more of about 230 codes. The most frequently reported medical conditions include being overweight, high blood pressure, and electrocardiogram results.

Who has Access to My Medical Records?

Your medical information contained in the MIB may be shared by a wide range of people both in and out of the health care industry. Generally, access to your records is obtained when you agree to let others see them. You have probably signed "blanket waivers" or "general consent

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forms" when you have obtained medical care. When you sign such a waiver, you allow the health care provider to release your medical information to insurance companies, government agencies and others.

1. Insurance companies require you to release your records before they will issue a policy or make payment under an existing policy. Medical information gathered by one insurance company may be shared with others through the Medical Information Bureau
2. Government agencies may request your medical records to verify claims made through Medicare, MediCal, Social Security Disability and Workers Compensation.
3. Employers may obtain medical information about their employees by asking employees to authorize disclosure of medical records. This can occur in several ways.
 - a) When medical insurance is paid by employers, they may require insurance companies to provide them with copies of employees' medical records.
 - b) Self-insured businesses establish a fund to cover the insurance claims of employees. Since no third party is involved, the medical records that would normally be open for inspection by an insurance company may be accessible to the employer. Most large corporations are self-insured.

Consumer Rights and the MIB

Currently, there is no comprehensive law regarding medical records privacy. You can however, check the accuracy of the information in your Medical Information Bureau report. The MIB database has records on only one or two out of every 10 people who apply for individual insurance. However small that number sounds, its database contains files on somewhere around 16 million people. How accurate are those records? The MIB admits that the exact number is hard to pinpoint, but estimates that about 3% of its records contain errors. The MIB is similar to a consumer credit reporting service, and has been accountable under the Fair Credit Reporting Act (FCRA) since 1995.

How to Get Your Records From the MIB

To obtain your record, log onto: www.mib.com/html/request_record.html. There is a charge of \$8.50 for each request for a Record Search and Disclosure. MIB will waive its charge for Record Search and Disclosure if you received a written notification of "adverse action" from an MIB member insurance company.

The Alpha-1 Research Registry

Dear Alpha,

Are you a member of the Alpha-1 Research Registry? If so, and you have not been in contact with us in the last year we are asking you to update your record. If not, we're asking you to read this article carefully and consider signing up!

The Alpha-1 Research Registry is a confidential database of over 1100 individuals with Alpha-1 or a carrier phenotype. We are happy to inform you of the inclusion of carriers in the Registry as a new addition in spring 2001. Registrants are located all over the US and in foreign countries as well. Check out our website at www.alphaoneregistry.org to see a map of Registry members in the US. To sign up or update your record call the Registry site (located at the Medical University of South Carolina in Charleston) toll free at 1-877-886-2383, email at alphaone@musc.edu, or visit our website for assistance.

What does enrollment entail? It is important to realize that every member is only asked to consider participation in a study when called upon. Participation in research is never a requirement. Also, there are many levels of contribution. Simply filling out the enrollment application provides us with valuable demographic and medical information. Some studies are as easy as filling out a questionnaire in the comfort of your own home. Those members able to travel to a study site will have opportunities to participate in clinical trials for new medicines and treatments. The purpose of the Research Registry is to provide researchers with Alphas and carriers willing to participate in research. As you can see, research will come in many forms with different levels of commitment from Registry members.

So your next question is probably, how confidential is this database? Dr. Charlie Strange, the Registry Director, and Ryan Dickson, the Registry Coordinator, are the only two people who have access to your Registry record. Your record is entered into a password-protected database inaccessible from the Internet, while the paper copy of your Registry application is kept under lock and key. There are also precautions in place for applying or updating your record on-line. Be assured your name and other personal information will never be disclosed to any researcher without your permission.

Why should I sign up or maintain member status? The Research Registry is a core program of the Alpha-1 Foundation. It was established to provide research incentives for scientific investigators to easily contact individuals with Alpha-1. Since Alpha-1 is a relatively rare disease, the ability to contact a large number of Alphas increases the likelihood of research in Alpha-1 and the Registry's desirability as study tool. Your participation aids us in the common goal to find a cure for Alpha-1-Antitrypsin Deficiency.

Sincerely,

Ryan Dickson, *Alpha-1 Registry Staff*

If they have information on you, the report will include the following information and can be received in 3 different ways:

- 1) the nature and substance of information, if any, that MIB may have in its files pertaining to you;
- 2) the name(s) of the MIB member companies, if any, that reported information to MIB; and,
- 3) the name(s) of the MIB member companies, if any, that received a copy of your MIB record during the twelve (12) month period preceding your request for disclosure.

Resources:

Privacy Rights Clearinghouse has an excellent fact sheet titled "How Private Is My Medical Information?" on the Internet at: www.privacyrights.org/fs/fs8-med.htm.

Institute for Health Care Research and Policy, Georgetown University. This organization sponsors the Health Privacy Project web site: www.healthprivacy.org. A leader in fighting for patients' privacy rights is the **National Coalition for Patient Rights**: www.nationalcpr.org

For more information, the home page of the Medical Information Bureau is found at: www.mib.com. Their mailing address is: MIB, Inc., P.O. Box 105, Essex Station, Boston, MA 02112

Patient's Corner

This is a new feature that will feature a short vignette of how Alpha-1 patients are coping positively with the disorder. Our first featured individual is AlphaNet Coordinator, Victoria Cameron. If you have a story to share, please contact your AlphaNet Coordinator for possible inclusion in a future column. We'd love to hear from you.

"I always get a laugh when I tell people that I take tap dancing lessons; when they realize I'm not joking they say I couldn't do that, and I say maybe you could! The love of dance is something that many of us share and miss doing.

I have to wear O₂ while tapping but I do not have a problem with that and neither do the others in the class. My teacher is very considerate; if she sees me struggling she takes a few minutes to talk to the class and lets me catch my breath. There is nothing like moving your feet to the rhythm of music for lifting your spirits and easing stress. I encourage others to try dance as a form of exercise.

I faithfully walk on the treadmill and ride my bike when the weather permits (usually around the yard if I'm alone), but it's dance that keeps me going. I can do almost anything I want because I have the Total O₂ Oxylite System which is lightweight and easily refilled from my concentrator. And I truly try to focus on what I can do rather than on what I can't do."

Alphas Serving Alphas

By Lucy Mitten

I want to thank Mary Pierce for calling me when I didn't want to be called, and for asking how I was doing when all I wanted to do was sleep for weeks at a time last year. I don't even remember when she first called me, but when she asked me what was a good time to call, I told her I took a lot of naps! For many months I hid in my bed for 12-16 hours a day, but Mary kept calling. I didn't tell her I was sleeping so much, but I'm sure she knew.

Then I started talking a little to Mary and she slowly became a lifeline for me. She probably didn't even know it. She helped me find a new doctor after I had an allergic reaction to Prolastin last December. She told me about the Alpha-1 Association's WEBTV program and gave me a number to call; that's what I'm typing on now.

Thank you Mary and everyone else who cared, even when I didn't.

Right now I feel like I'm going to erupt with my alpha story, but I'll be sharing it as we go along. I'm the 4th in my family to have Alpha-1. Three older brothers are dead; one had liver involvement and was on the liver transplant list in 1987.

Thanks for listening... (Yes, I'm ZZ.)

Kayak for Kids 2001



May 4-14, 2001, Tom Dailey and Mary Pierce paddle ashore in Amityville, NY completing their 10 mile kayak trip around the eastern end of Long Island to raise awareness of Alpha-1 Deficiency and to raise funds for research.

Coordinators Wanted

AlphaNet is currently expanding its staff of Coordinators. Successful candidates will be self-motivated, have excellent communications and computer skills and possess an in-depth knowledge of Alpha-1 Antitrypsin Deficiency.

AlphaNet Coordinators work in their homes and provide a wide range of services to Alphas, including assistance with infusion supply inventorying and ordering, insurance counseling and coordination of pharmaceuticals and other medical support services. Interested Alphas should fax their resumes to (305) 442-1803, or e-mail resumes to: humanresources@alphanet.org

Nurses' Corner

By Janis G. Berend, MSN, C-ANP

I have had nurses calling to ask what they should do if their patient has no Prolastin. Even though Prolastin has begun shipping again, it is important to discuss this issue since these shipments are likely to be coming on a somewhat sporadic basis. Patients with Alpha-1-Antitrypsin Deficiency have a low level of the alpha-1-antitrypsin protein (AAT). The low level they do have still provides some protection to the lungs. We know this because some Alpha-1 patients never develop lung or liver disease. Prolastin augments the amount AAT in the circulation and the tissues. Prolastin is just one aspect of a complete management approach to Alpha-1 and the patient needs to follow the other suggestions of their healthcare providers to help remain as healthy as possible and prevent further lung destruction.

Maintaining a protective screen of AAT to fight the action of the destructive white blood cell elastase is always the goal whether on or off Prolastin. The following are ways to help your Alpha-1 patients stay healthy and avoid infections.

Individuals with Alpha-1 should:

- Report any lung infection symptoms promptly to their healthcare provider.
- Remain current with flu and pneumonia vaccinations.
- Understand their medical regimen and their medications.
- Maintain a good exercise program. Exercise will help keep airways clear of secretions, improve energy levels, and improve muscle strength and efficiency, especially of the respiratory muscles.
- Be diligent in avoiding all cigarette and other tobacco smoke, inhaled irritants (such as dust, fumes, and pollutants), and stressful situations.

- Avoid areas with poor ventilation and crowds of people such as airplanes, indoor concerts, and hospitals. Think before you do something that might expose you unnecessarily.
- Frequently wash hands with soap and water. Keep hands away from your face.
- Avoid getting overly tired. Alcohol can also reduce your resistance (no all night parties).
- Wear a mask if you have questions regarding your exposure. Have them with you so you are not caught off guard.
- Maintain a positive attitude.

Discuss these issues with your patient and help them sort out their concerns. Find things they can do to help to feel less vulnerable. Please call if I can be of any help.

Director of Nursing, AlphaNet
Janis G. Berend, MSN, C-ANP
(800) 577-2638 ext. 220

The Clean Air Challenge Trek



The Clean Air Challenge Trek is an annual ALA event that takes place each May, beginning in Portsmouth, NH and along the sea coast of Maine. For the past two years Richard O'Brien, Vicki Cameron's son-in-law, has ridden for Team Alpha. The entire family enjoys welcoming the riders across the finish line on Sunday! This year the cheering section was increased by members of the newly formed support group in NH, The Granite State Puffers.

Pictured are (l to r, back row) Vicki C., Cindy Bowman, Kathy O'Brien, Mykayla O'Brien on Aunt Traci's shoulders, and Bruce C.; (front row) Spencer O'Brien, Devinne G., Team Alpha Rider, Richard O'Brien, and in the buggy, Logan O'Brien. Missing are Tom and Bunny Bell with their grandson and a number of Shirley Dennis' relatives.

Team Alpha was well represented with upwards of a dozen members on the team. They all did a great job and deserve our appreciation.

Events Calendar

◆ Alpha-1 Education Days Fall 2001.

Alpha-1 Education Days are held in geographically diverse regions of the U.S. Each program includes speakers on a variety of Alpha-1 related medical topics and research activities.

- August 18, 2001 — Hanover, NH
- September 15, 2001 — Oakland, CA
- October 14, 2001 — Portland, OR
- October 27, 2001 — Cleveland, OH

For more information on Alpha-1 Education Days please contact Dona Schneider, Alpha-1 Association, at (800) 521-3025, email "dschneider@alpha1.org" or Marlene S. Erven, Alpha-1 Foundation, at (888) 825-7421, ext. 211, or email "mserven@alphaone.org"

◆ August 25th, Whale Watch, fundraiser for the Alpha-1 Foundation, out of Salem, MA; the boat sails from Pickering Wharf. For information contact Kimberly Spires at 617-526-1730.

◆ September 21-23, 17th Annual ALA Autumn Escape Bike Trek from Plymouth, MA to Provincetown, MA. Contact Martha, Meg or Mary at the ALA office, 508-668-6729 or email: lungusa2@earthlink.net

AlphaLetter

Alex and Irene Sandor are retired and living in Las Vegas. Alex has a unique variant of Alpha-1 and so it was difficult to get approval for his Prolastin and resulting infusion therapy. Finally, with the help of many, Alex is now able to continue his treatments. Alex and Irene asked that we print their thank you.

Dear AlphaNet,

Alex and I want to thank Dr. Bruce Moody, Terry Young, and Fred Walsh and everyone else who helped us with their counsel and resolution of Alex's Prolastin and infusion coverage. The list of people who got involved is enormous from local help here in Nevada and throughout other states. Everyone has been so nice, understanding and helpful! We hope this letter is read by all our friends in AlphaNet and again, thank you very much.

Sincerely,

Alex and Irene Sandor

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

Team Alpha at The Autumn Escape, 2000



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Return Service Requested

