



SPRING 2010

AlphaNet, Inc.

2937 SW 27th Ave., Suite 305
Coconut Grove, Florida 33133
800-577-2638, Fax: 305-442-1803
www.alphanet.org

COORDINATORS:

- Roger R. Bray** 877-227-7914
rbray@alphanet.org (KY, TN)
 - Patti A. Brown** 877-264-7470
pbrown@alphanet.org (TX)
 - Linda L. Caly** 877-710-0915
lcaly@alphanet.org (MN, WI)
 - Victoria (Vicki) S. Cameron** 888-526-0351
vcameron@alphanet.org (ANC's)
 - Dan J. Clark** 888-225-9012
dclark@alphanet.org (MI)
 - Jennifer (Jenny) L. Fauli** 866-697-8530
jfauli@alphanet.org (Zemaira, Eastern USA)
 - Kathleen (Kathy) A. Haduck** 800-813-4494
khaduck@alphanet.org (DE, PA)
 - Patricia (Pat) E. MacInnes** 877-277-7931
pmacinnes@alphanet.org (NY, NJ)
 - Jean M. McCathern** 888-526-9077
jmccathern@alphanet.org (ME, VT, NH, CT, MD)
 - Celeste B. Morris** 877-330-4506
cmorris@alphanet.org (At-Large)
 - Marianne K. Mullen** 866-940-3411
mmullen@alphanet.org (AZ, ID, MT, NM, UT, WY)
 - Diana J. Patterson** 888-399-0443
dpatterson@alphanet.org (South FL, PR, USVI)
 - Barbara J. Pusey** 800-745-3004
bpusey@alphanet.org (Zemaira, Western USA)
 - James (Jim) A. Quill** 888-795-6393
jqull@alphanet.org (IN, SC)
 - Sandy L. Singleton** 877-898-8630
ssingleton@alphanet.org (CA, HI, AK)
 - Kathleen (Kathie) D. Sivesind** 866-244-1026
ksivesind@alphanet.org (NV, WA, OR)
 - Sue K. Smith** 888-883-2991
ssmith@alphanet.org (OH, WV)
 - Kay Swift** 877-742-9078
kswift@alphanet.org (NE, ND, SD, CO)
 - Patricia (Patty) Tew** 877-271-3001
ptew@alphanet.org (GA, North FL)
 - Gayle Allison Tipper** 877-982-5742
gallison@alphanet.org (NC, VA, DC)
 - Jane Totten** 866-477-1552
jtotten@alphanet.org (At-Large)
 - Douglas (Doug) K. Turley** 877-943-9828
dkturley@alphanet.org (IA, KS, MO)
 - Elizabeth (Liz) A. Veronda** 888-723-9487
lveronda@alphanet.org (IL)
 - Marilyn Wagner** 866-556-6622
mwagner@alphanet.org (AL, AR, LA, OK, MS)
 - Fred C. Walsh** 800-791-3194
fcwalsh@alphanet.org (MA, RI)
- STAFF:**
- Robert C. Barrett**, Chief Executive Officer
800-577-2638 ext. 229 rbarrett@alphanet.org
 - Robert A. "Sandy" Sandhaus, MD, PhD, FCCP**
Medical Director, Executive VP
800-577-2638 ext. 226 rsandhaus@alphanet.org
 - Terry L. Young**, General Manager
800-278-1804 tlyoung@alphanet.org
 - Bonnie S. Boyd, BS, RN**, Director of Disease Management & Clinical Research
877-913-8141 bboyd@alphanet.org
 - Janis G. Berend, MSN, C-ANP**, Nurse Case Manager
800-577-2638 ext. 220 jberend@alphanet.org
 - Teresa A. Kitchen, BSN, RN**, Clinical Nurse Manager
888-553-0093 tkitchen@alphanet.org
 - Edward J. Parker**, IT Manager
800-577-2638 ext. 257 eparker@alphanet.org
 - Monica M. Martinez**, Human Resources Manager
800-577-2638 ext. 247 mmartinez@alphanet.org
 - David J. Gruszka**, IT Support Specialist
800-577-2638 ext. 260 dgruszka@alphanet.org
 - Rebecca E. Lillian**, Research and Program Coordinator
800-577-2638 ext. 318 rlillian@alphanet.org
 - Lindsey N. Griffin**, Executive Assistant
800-577-2638 ext. 243 lgriffin@alphanet.org

The AlphaNetter

The AlphaNetter is a publication of AlphaNet, Inc.



Prolastin is Now Prolastin-C

By Robert A. "Sandy" Sandhaus, MD, PhD, FCCP, Medical Director, AlphaNet

As most Prolastin users now know, there has been a change in their product. Prolastin is being phased out and replaced by Prolastin-C, a product that applies the latest methods to the purification of alpha-1 antitrypsin from plasma. According to what is in the information provided by the manufacturer, Talecris Biotherapeutics, and the literature that comes with the new product, there are a number of differences between Prolastin and Prolastin-C.

The most obvious difference is that a vial of Prolastin containing about 1000 milligrams of alpha-1 antitrypsin needed to be diluted with 40 milliliters (about 1 and 1/3 ounces) of water while the same dose of Prolastin-C is only diluted with 20 milliliters (about 2/3 ounce). This is the same volume as Zemaira, the CSL Behring product, and less than half the volume of Aralast NP from Baxter Healthcare. This decreased volume may allow many patients to shorten the time an infusion takes, often cutting the time in half.

Talecris also reports that Prolastin-C has a higher purity than Prolastin. That means that there are lower levels of plasma proteins other than active alpha-1 antitrypsin in each vial compared with Prolastin. The package insert states that the purity of Prolastin-C is at least 90%. This is the same as the listed purity of Zemaira. Aralast NP does not include purity data expressed in this way in its package literature.

The manufacturing processes that were changed for the production of

Prolastin-C allow Talecris to extract more active alpha-1 antitrypsin from each unit of plasma than they could with the older method. Among the changes are differences in the purification steps as well as changes to some of the methods used to eliminate and inactivate viruses. Prolastin used microfiltration and heat inactivation for reducing the risks of viral transmission, while Prolastin-C uses nanofiltration and solvent-detergent treatment.

The U.S. Food and Drug Administration (the FDA) approved the move from Prolastin to Prolastin-C based on two studies comparing the safety and biochemical efficacy of the two versions of the product. Biochemical efficacy means the ability of these products to raise the level of alpha-1 antitrypsin protein in the blood and the lungs.

The companies working in the Alpha-1 community continue to monitor the safety of their products and to improve the manufacturing procedures as technology advances. If you notice any problems or side effects from the treatments you are receiving, please be sure to let the company that makes the treatment know. You can usually find contact information for the manufacturer on the box or bottle the product comes in. Your AlphaNet Coordinator can help you report any side effects and help direct you to find ways to minimize any side effects in the future.

Prolastin has been available to the Alpha-1 community for over 20 years. It has had a remarkable record of safety during that time. We expect that those on Prolastin-C will find it to be a worthy successor to the Prolastin they were receiving before.

Mohawk Ramblers Bike Run



Frank Lumbis with his dog, Benjamin.

Biker Frank Lumbis is taking the battle for breath to the road and he is getting others involved. Every year on the first Saturday in June, you'll find Frank at the Alpha Bike Run. After an optional 50-75 mile run (on their motorcycles) participants meet up at the Mohawk Ramblers Motorcycle Club in Greenfield, Massachusetts for a barbeque, a silent auction, music and motorcycle games. All the proceeds from the event go to the Alpha-1 Foundation to support Alpha-1 research.

Frank was diagnosed with Alpha-1 in 2006, after his mother was tested and diagnosed. Prior to that, Frank worked as a concrete finisher for 24 years. Now he meets up with mom at the local hospital for weekly infusions. "I'm a real loner," Frank says, "but you know, anything for mom."

After being diagnosed, Frank was eager to get involved. He first dreamed up the Bike Run in 2008 and pitched it to his motorcycle club to sponsor. Now in its third year, Frank is excited to see participation grow. "We're hoping to get more people involved this coming June. Last year we had Alphas, Docs and members of the club show up. Everyone is welcome."

Transplant Q&A with Dr. Robert Love

Dr. Robert Love is a cardiothoracic surgeon with vast transplantation experience and the Medical Director of Lung Transplantation at Loyola University Medical Center. In the past 20 years, Dr. Love has performed over 1,000 lung transplant surgeries.

Can you explain why age 65 has been considered the unofficial "cut-off" for lung transplants in the past and what is making it possible to perform transplants on individuals age 70 and above?

The age range for patients receiving lung transplants has continued to expand on both the donor and recipient side as it has for every other solid organ transplant. Twenty-five years ago, when I started, we didn't want donors over 30 or recipients over 50 for transplantation. Now, isolated heart and lung transplants are being done routinely on patients over age 70 and experience is showing us that selected older patients can do just fine. Transplantation has evolved as the expertise and technical aspects of the operations have been standardized and as we have gained experience in properly matching recipients and donors. Age is not a criterion to exclude someone for transplantation in and of itself; there are always other factors to help us decide to pursue transplant or not to pursue transplant.

Is it becoming more common to perform transplants on individuals over 65 or is this unique to your facilities?

In high volume transplantation programs, such as Loyola's, age has become a secondary characteristic. It is still an important factor, but has not been a sole reason for not transplanting a patient. Most transplant programs in the country do less than 10 transplants a year. These smaller programs tend to be more conservative with age. Patients who are older will add risk and put pressure on program results.

How many transplants does Loyola perform annually and how many are you involved with?

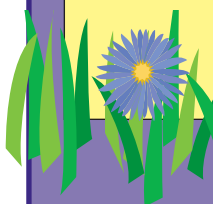
Loyola performs about 50 lung transplants a year. I am involved in all of them. I am involved in the actual surgery for about two-thirds of our cases. When I worked at the University of Wisconsin, I performed all the surgeries.

What was the age of your oldest transplant patient?

My oldest single-lung transplant patient was near 75. I believe single-lung transplants have been performed on individuals over 80 in other programs. My oldest heart-lung block transplant patient was in their upper 50s, probably 58. Generally for heart-lung transplants, age is a criterion. Fewer heart-lung blocks are done, maybe 40 per year in this country. For these situations, we are much more conservative with age and everything else.

You performed transplant on Howard Matson in November 2008 (age 71). Why did he fit the bill for transplant?

Mr. Matson's level of physical activity and fitness, which he maintained as a habit in his life, helped him to



maintain health while his lungs were deteriorating. Not everyone at age 71 has such high general health. This habit in his life was important in the decision. Mr. Matson also exhibited a very strong faith that was a routine part of life and a realistic outlook on his illness and future issues that may be related with

transplant. He understood that transplant is not a decision to be taken lightly; we look for that in all of our patients. These were not the only factors. Mr. Matson has a tremendous family and social support system that is active. We knew after transplant he would have help taking care of himself, transportation for

routine visits and people looking after him and holding him accountable. Transplant is a big adjustment and these are brave people who do pursue it.

What encouragement/advice can you offer those interested in transplant?

The Alpha-1 community is typically well-educated about their disease and their available support systems. I would advise those interested in transplant to apply that knowledge and experience to the question of whether or not to consider transplant. Don't be afraid to look at data from center to center, volume, results, and what centers take patients with a spectrum of risk. Then educate yourself further by talking directly to a patient who has had a lung transplant. I suggest this to each patient that I consult with. I have transplanted 1,000 lungs, but I've never had a transplant myself. I can't give information on the same level as a transplant patient.

I also recommend that patients attend pulmonary rehab even if their insurance won't pay for it. Get what you need to understand how to exercise. Get a pulse oximeter. Don't stop working hard and looking forward to the future. Keep up mental and physical fitness. I encourage patients to become involved in an Alpha-1 or lung support group. Those who have been a part of Alpha-1 support groups can attest that these have helped them to remain mentally and physically able to cope. We in the transplant world welcome Alpha-1 patients to be evaluated, to ask questions, and to explore the possibilities.



Howard Matson and his wife, Nancy, stroll down Michigan Avenue in Chicago.

71-Year-Old Receives New Lung

Retired pastor Howard Matson believes in miracles and with good reason. When he first began pursuing lung transplant at age 70, his age alone might have disqualified him from some programs, not to mention the shopping list of additional health and lifestyle factors for which he was later screened and the battery of tests he had to undergo before his name was added to the transplant list.

“One of the concerns for a person my age was that my body would not be able to handle this kind of surgery,” Howard says. “I had been a runner all my life and, even as my disease has progressed, I continued to exercise regularly, though more slowly. I really believe that is what made it possible for me to have this surgery at my age.”

In November of 2008, at 71, Howard received a single-lung transplant at Loyola University

Medical Center (LUMC) and with it, a new life.

“I experienced no pain from the operation and I woke up with a new lung,” Howard says. “A week later, the physical therapist took me for a ten minute walk without oxygen. When I sat down, my pulse oximeter had me at 97%.”

After being diagnosed with Alpha-1 in 1995 and using supplemental oxygen since 2002, Howard marvels at the drastic change in his quality of life. In January, he preached a sermon for the first time in four years. He is planning a trip to St. Petersburg, Russia, Norway and Sweden with his wife, and he is still exercising.

Howard says, “I am going to stay persistent and continue to value and care for my body and this incredible gift.”



Alphas Hit the Hill

Alpha and Respiratory Therapist (RT), Amy Chaves, represented Massachusetts at the American Association for Respiratory Care (AARC) advocacy day in Washington D.C. on March 9th. As part of the event, alphas paired with an RT from their state and hit Capitol Hill to meet with legislators. Participants lobbied for expanded Medicare benefits to allow patient access to qualified Respiratory Therapists outside the hospital setting and for increased Federal Response to COPD.

“As patients, we were able to talk about how our Alpha-1 has affected us personally and to give insight into how these reforms will serve our community,” Amy says. “Many of us have taken responsibility for our own disease management because our primary physicians are less familiar with our disease. Our level of education about our disease makes us powerful advocates; however, we are such a small community that we must speak for ourselves to be heard.”

Amy has made the trek to Capitol Hill to participate in advocacy campaigns for the past four years. She first became involved as a member of the Rhode Island Society for Respiratory Care and has lobbied as an RT. This was her first time participating as an Alpha-1 patient.

Amy was diagnosed in 2000 while working as an RT in a hospital. When her symptoms began to interfere with work, Amy administered her own pulmonary function test and asked a pulmonologist to review the anonymous results. The pulmonologist suggested that the individual with the results be tested for Alpha-1. Amy took that information to her primary care physician, was tested and diagnosed.

As an Alpha, who also happens to be an RT, Amy recognizes the positive impact of the D.C. event on multiple levels.

“Even the small contact between Alphas and RT's at this event allowed for some off-the-cuff education,” she says. “I was able to teach one individual how to use their inhaler. Another RT noticed that a gentleman was wearing his cannula backwards and was able to instruct him in proper use. Overall the reception on the Hill was very positive and first-time participants expressed an interest in continued involvement. This kind of reform is not something you can expect to go quickly. You have to keep going back and you have to continue to build relationships with legislators and their aides throughout the year.”

For more information on grassroots advocacy or to learn how to become an advocate visit the Alpha-1 Association website www.alpha1.org and the American Association for Respiratory Care website www.aarc.org/advocacy

Managing Your Prolastin-C Infusion Supply Inventory

By Jim Quill, AlphaNet Coordinator (IN, SC)

If you receive home infusions, your AlphaNet Coordinator contacts you or your nurse quarterly for a supply inventory. Here are some suggestions on how to make this process easier and more accurate.

1. When you receive your infusion supply order, organize the items into zip lock bags. Each bag should contain the items needed for one infusion. (You may want to work with your nurse at first to set this up. Your nurse can tell you what items should go into each bag if you are not sure.)
2. When the nurse arrives for your scheduled infusion, you will have a bag containing the necessary supplies ready and waiting. No need to search around in a box or drawer for individual items.
3. When your Coordinator calls for an inventory, tell them how many bags you have remaining. No more rummaging and counting individual supply items.

When your Coordinator is able to get a correct inventory from you about your supply needs, it minimizes the chances of sending an incorrect order. Incorrect orders may cause a shortage in needed supplies or a storage problem for you if too many supplies are received.

Some patients prefer that their nurses complete their inventories; however, nurses are not always easily accessible by phone because they serve many patients with various needs. Calls to nurses are not always returned to your Coordinator. When this happens, your Coordinator submits a standard order that often will not reflect your current supply needs.

Taking responsibility for your own infusion supplies will help save you time, effort, and storage space.

Exercise elevates my mood, allows me to eat more treats, and helps me stay in my clothing size range. I enjoy fast walking in 5k charity events. My husband and I walk about 4 miles a day and it is a great together time for us. I can't imagine not exercising. - **Sue**

I like to do fun activities with other people that are considered exercise (ice skating, walking, badminton). I'm not crazy about exercise, but I'm very social. - **Jean**


My promise to the SFS Study to do at least 20 minutes 3 times a week. Were it not for this, I think I might not do it. - **Geraldine**
P.S. I feel great when I do.

I attend three-hour Zumba classes each week. Zumba is a cross between hip hop and Latin dance. I love music and it's easy to adjust my workout intensity. I can slow down if I need to or go all out. Either way, I'm moving! - **Lucinda**

What Motivates YOU to

I exercise for love. I love my wife, my 3 children, 4 grandkids and life. - **George**


I attend a fitness class on a regular basis. People get to know me and hold me accountable when I miss by asking "Where were you?" Also when I'm in a class, the time is already set aside so I don't make plans during that hour. - **Dottie**



I have found the Wii to be a great way to exercise. It provides a variety of activities that are a lot of fun to do and they help to break up the monotony of the treadmill. My wife and I enjoy exercising together and we motivate each other - **Larry**

I want to keep healthy, lessen my dependence on supplemental oxygen and continue to be able to do the things that I enjoy. - **Jeff**

I record all of my "guilty pleasure" TV shows (for example, the Maury: "You are the father!" Povich) and I only allow myself to watch them while I am on my treadmill. - **Bonnie**



The pedometer in my pocket that keeps calling me a wimp unless I take more steps. - **Ken**

I've been going to a pulmonary rehab program for 9 years. I exercise because it helps increase my strength, stamina and endurance. Ultimately it makes me feel great and able to move and last longer all day! You cannot beat that feeling. - **Tony**

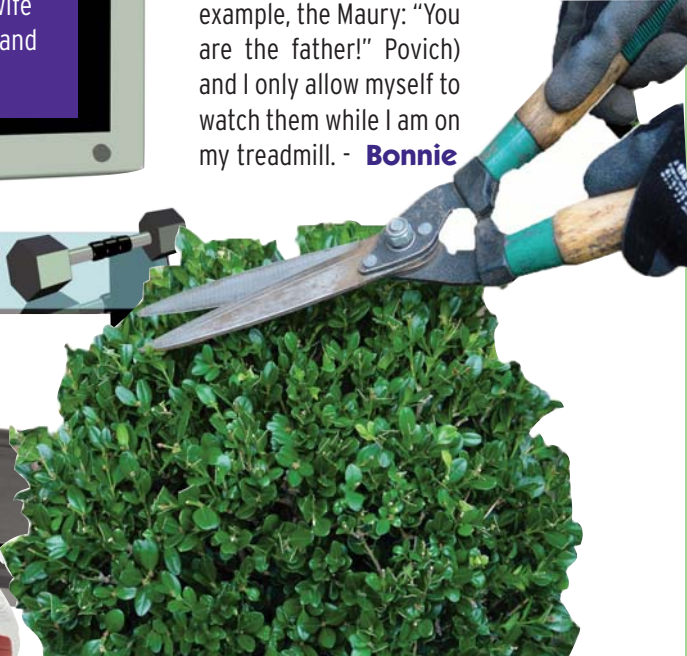
- **Tony**

I'm motivated by music, specifically classic rock, but any music will get me going! - **Bill**

Exercise is an important part of my health routine, just as important as my inhalers or augmentation therapy. If I stop exercising I will lose the tolerance I have built up. For me, that is not an option. - **Caroline**

My husband and I came up with "Commercial Workouts". Every time a commercial comes on we get up and workout. These short bursts for up to two hours in the evening are working great! I've lost over 10 pounds and I feel so much better physically and mentally! - **Jennifer**

Exercise?



I am motivated to exercise when I can accomplish something while doing the exercise, like cut the grass, trim a tree or walk to do an errand. - **Wayne**

I exercise to be normal and to be seen and considered no different than any other female in her mid-fifties. I exercise for myself, to feel as if I can make a difference in the way this disease wants to control me. Two of my three children have also been diagnosed with Alpha-1 and I want to show by example that the disease is manageable. That is why I exercise. No one is going to take care of my body or know its limitations the way I do. It's my body and my responsibility! - **Diane**

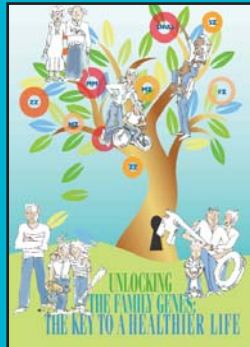
Community Calendars

Alpha-1 Association Education Days

co-sponsored by
the Alpha-1 Foundation

August 28
Des Moines, Iowa

September 25
Las Vegas, Nevada



Alpha-1 Association National Education Conference

June 11 - 13
Orlando, Florida

To find out more about conferences and support groups, visit the Alpha-1 Association website at www.alpha1.org or call toll-free: (800) 521-3025.

AlphaNet Employment Opportunity

Do You Have What It Takes?

Applications are currently being accepted for employment as AlphaNet Patient Service Coordinators. Interested Alphas should be dedicated, organized professionals who are able to travel and demonstrate strong computer and communication skills.

Send resumes to humanresources@alphanet.org

Alpha-1 Foundation Event Calendar

April 30 - Alpha-1 Foundation
Celebration of Life
Indian Creek, Florida

May 8 - 3rd Annual New York & New Jersey
George Washington Bridge Walk
New York, New York

May 18 - AlphaOkies Silverhorn
Golf Tournament
Oklahoma City, Oklahoma

June 5 - Alpha Bike Run:
Mohawk Ramblers Motorcycle Club
Greenfield, Massachusetts

To find out more about these or other events in your area, log onto www.alphaone.org or call toll-free: (888) 825-7421, ext. 248.



2937 SW 27th Ave, Suite 305
Coconut Grove, Florida 33133
800-577-2638 • www.alphanet.org
Return Service Requested