



SPRING 2010

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The AlphaNetter

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Zemaira Coordinators Tour CSL Plant

In March, AlphaNet Coordinators Barb Pusey (Western USA) and Jenny Faull (Eastern USA) joined Alphas, caregivers, AccessMED representatives and CSL Behring representatives from ten different states to tour the CSL Behring Plant in Kankakee, Illinois and to see how Zemaira is manufactured. Both Barb and Jenny infuse Zemaira.



Dave Pusey, Barb Pusey, Diane Angell, Jenny Faull and Doug Faull tour CSL Plant.

Tour participants attended a dinner, where visiting Alphas shared personal testimonies about their journey to Alpha-1 diagnosis and beyond. The following day, participants were warmly welcomed to the CSL Behring Manufacturing Plant by Senior Vice President and General Manager, Walter Casey, and other staff. Dr. Scott Kee, Senior Manager of Bioanalytical, presented about the Zemaira manufacturing process. A question and answer session followed.

“It was evident that the CSL personnel really wanted to know what it was like for us to live with Alpha-1 and to hear how Zemaira impacts our lives,” said AlphaNet Coordinator Barb Pusey. “It was an intimate moment for us Alphas to share our experiences with complete strangers whose jobs really impact our day-to-day living. They seemed genuinely pleased that their hard work was beneficial to us.”

After the Q&A, Alpha and CSL Patient Service Specialist, Diane Angell, demonstrated the technique of reconstituting Zemaira with sterile water using the color-coded transfer device. Dialog continued over lunch, which was followed by a plant tour.

Barb recalls, “We were escorted through a spotless building. Each step in the manufacturing process was described, from the entry of the donor product to the final steps of filling, inspecting and packaging our Zemaira vials. Glass windows separated us from the intricate piping and machinery that was, even then, refining the product. CSL was gracious enough to allow us to don “clean room” apparel and enter into a filtration room. Covered from head to toe with hair nets, paper gowns, eyeglasses, and disposable shoe covers, we could hardly recognize each other. It made me grateful for the extreme measures taken to ensure the quality of the end product.”

“Not only was the manufacturing facility itself impressive, but even more remarkable was the attention given to every detail and every process to ensure that the Zemaira we’re infusing is of the absolute highest quality. The peace of mind that gives us is priceless,” says Coordinator Jenny Faull, “Walter Casey stated to us that ‘CSL Behring is committed to excellence’ and it showed.”

Tours are scheduled three times a year. Airfare, ground transportation and lodging for one night are provided by CSL Behring. Any Alpha interested in a plant tour should contact their AlphaNet Coordinator.

AlphaNet provides health management services at no cost to Zemaira patients. If interested, call Barb Pusey 800-745-3004 or Jenny Faull 866-697-8530.

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?

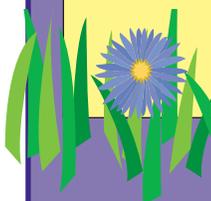
Loyola performs about 50 lung transplants a year. I am involved in all of them. I am involved in the actual surgery for about two-thirds of our cases. When I worked at the University of Wisconsin, I performed all the surgeries.

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 Home Infusion Supply Inventory

By Jenny Faull, AlphaNet Coordinator (Eastern USA)

If you receive home infusions, your pharmacy (either Accredo or Coram) contacts you monthly for a supply inventory. Here are some suggestions on how to make this process easier and more accurate:

1. The pharmacy representative will ask you how many doses of Zemaira you have left and will confirm your infusion days to make sure that there is no interruption in your infusion schedule. You will also be asked if you need any extra supplies, if your SHARPS container is full, and if you have had any changes in your medications, weight or health status (i.e. any infections in the past month). Finally, the pharmacy representative will confirm the date that your Zemaira and infusion supplies will arrive. If you have any questions about your supplies, your nurse as well as your AlphaNet Coordinator will be more than willing to help you.
2. Once your Zemaira and infusion supplies have arrived, make sure to bring the package inside to avoid exposure to extreme temperatures. You should open the package as soon as possible and make sure that the order has shipped in its entirety. Save the packing slip that came in your shipment in case you need to review the shipment later on.
3. Pre-sorting the supplies needed for each infusion into “kits” is a big help and time saver for your nurse as well as for you when the pharmacy calls each month for your order. One Bag + One Dose Zemaira = One Infusion. Once you have sorted your supplies and confirmed that all of the necessary items are present, you will want to place the kits and Zemaira in a designated box or drawer for easy access.
4. When your nurse comes for your infusions or when you self-infuse each week, be sure to note if you are running short on any supplies that may come in bulk, such as alcohol pad or gauze pads. Also check the expiration date on your EpiPen to make sure that it is not getting close to expiration. Your pharmacy will confirm that with you monthly as well. It will not take long for the ordering process to become routine.

To make the process go smoothly, organize your supplies as you receive them and return the pharmacy's call when they leave a message telling you it is time for your reorder. The sooner you reorder, the sooner you can rest at ease that your next month's supply is on its way.

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**

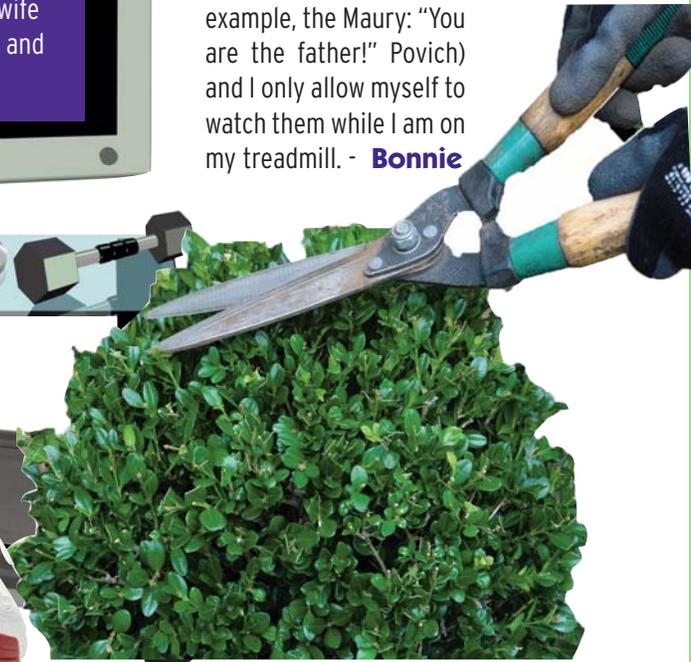
I attend a fitness class on a regular basis. People get to know me and hold me accountable when I miss by asking "Where were you?" Also when I'm in a class, the time is already set aside so I don't make plans during that hour. - **Dottie**



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**

Exercise?

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**

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.



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