

NIH Announces Genetic Testing Registry

Database to Fill Information Gaps and Serve as Research Resource

The National Institutes of Health announced that it is creating a public database that researchers, consumers, health care providers, and others can search for information submitted voluntarily by genetic test providers. The Genetic Testing Registry (GTR) aims to enhance access to information about the availability, validity, and usefulness of genetic tests.

Currently, more than 1,600 genetic tests are available to patients and consumers, but there is no single public resource that provides detailed information about them. GTR is intended to fill that gap. The overarching goal of the GTR is to advance the public health and research into the genetic basis of health and disease. As such, the registry will have several key functions:

- Encourage providers of genetic tests to enhance transparency by publicly sharing information about the availability and utility of their tests
- Provide an information resource for the public, including researchers, health care providers and patients, to locate laboratories that offer particular tests
- Facilitate genomic data-sharing for research and new scientific discoveries

“The need for this database reflects how far we have come in the last 10 years,” said NIH Director Francis S. Collins, M.D., Ph.D. “The registry will help consumers and health care providers determine the best options for genetic testing, which is becoming more and more common and accessible. Our combined expertise in biomedical research and managing such large databases makes NIH the ideal home for the registry.”

The GTR project will be overseen by the NIH Office of the Director. The National Center for Biotechnology Information (NCBI), part of the National Library of Medicine at NIH, will be responsible for developing the registry, which is expected to be available in 2011. GTR genetic test data will be integrated with information in other NIH/NCBI genetic, scientific, and medical databases to facilitate the research process. This integration will allow scientists to make, more easily and effectively, the kinds of connections that ultimately lead to discoveries and scientific advances.

During the development process, NIH will engage with stakeholders—such as genetic test developers, test kit manufacturers, health care providers, patients, and researchers—for their insights on the best way to collect and display test information. In addition, other federal agencies, including the Food and Drug Administration and the Centers for Medicare and Medicaid Services, will be consulted.

More information about the Genetic Testing Registry and NCBI is available at: <http://www.ncbi.nlm.nih.gov/gtr>.

NIH Senior Health Website

The National Institute of Health (NIH) has created a new exercise area on their website that is Senior friendly, but is equally impressive for those with limited abilities and challenging health. For anyone wishing to begin an exercise program, fire-up an existing plan or just make their current plan more challenging, the website offers easy to watch videos and testimonials to assist you.

The National Institute on Aging (NIA) created the videos and exercise programs focusing on four areas of need: endurance, strength, balance and flexibility. NIH institute directors are shown in the videos performing their favorite forms of exercise in bright colorful format. The videos offer a wide range of exercise approaches from stretching to biking and swimming.

From the press release: “When done on a regular basis, exercise and physical activity offer many health benefits and can be a pleasure, especially if you participate in physical activities you enjoy. “Numerous studies have shown that regular exercise and physical activity can reduce the risk of developing certain diseases and disabilities that can occur as people grow older,” says Richard J. Hodes, M.D., director of the NIA, which developed the exercise and physical activity topic. “In some cases, exercise can help manage and prevent diseases like diabetes, heart disease and osteoporosis.” Exercise also helps improve balance and helps people maintain their independence.”

To view this new approach, go to <http://nihseniorhealth.gov/exercise/toc.html>.

Phone Home on Us

To sign up for the program cosponsored by A1AA and Coram Healthcare, go to

http://www.alpha1advocacy.org/a1aa_phonocard_program.htm

or call us toll free at 1-866-367-2122.

Alpha-1 Advocacy Alliance

“Our mission is to improve the health and well being of those affected by Alpha-1 through support to patients, educating healthcare professionals, and advancing public policy for the Alpha-1 Community.”

Going Home to Stay

by Ann Marie Benzinger

My one day home had been anything but successful. After a Friday night admission to the University of Virginia determining I had contracted or developed cytomegalovirus (CMV), I was moved by ambulance back to the University of Maryland on Sunday evening. I spent the next week receiving anti-viral treatments for the CMV infection by IV and again suffering from stomach pain. Rounds of residents and transplant coordinators, gastric interns and doctors visited trying to determine what was going on with my stomach. They finally decided to run more tests looking for gall bladder issues (actually quite common in lung transplant patients), but I passed those tests. Nothing could be determined as a “definitive cause” so we all moved on, knowing that further problems would mean more aggressive testing. I was willing to face that down the road in hopes that time would improve my stomach distress.



My sister once again brought me home. It was now three months since my transplant. I was walking with a walker very slowly, but totally without oxygen. My balance, however, still proved challenging. Thanks to a raised toilet seat attachment, I could now visit the bathroom and get up from the toilet without assistance from anyone. My fine-motor skills were still inadequate and I struggled with eating utensils. I began walking short distances from the living room into the kitchen without the walker and back trying to build some strength in my legs. Repetition was key to building strength. It was difficult to get up from my upright wing chair. I needed to press hard down on the arms and sometimes I was just too weak and had to ask for assistance. My sister was there to help, thank goodness, preparing my meals and making sure I took my medicines correctly.

The medicine routine can prove challenging as many of you know. Some of the medicines must be taken on an empty stomach, while others need to be taken with food or plenty of liquids. The bulk of my medicines were for the stomach issues. As acid reflux is a known cause of chronic rejection, it was very important to make sure I did not have GERD or aspirate any food back into my lungs. I was taking cyclosporin, imuran and prednisone as anti-rejection drugs. In addition I took Voriconazole and Valcyte as anti-viral medicines against CMV and aspergillosis. I had a high-blood pressure pill, a sleeping pill as needed and pain medication as needed. I was also receiving daily IVs of gancyclovir for the CMV infection. I continued to use my inhalers, but as each day went by I noticed that I needed them less and less. The home health care nurse came three days a week and did blood draws once a week and

my daughter administered the IVs on the other days. I had an IV access line so I didn't have to be stuck daily.

At the end of the first week home, my sister had to leave and return to work. Her help cannot be measured. Anyone undergoing such a surgical experience is blessed to have a caregiver like Alice was for me. Words can never convey the appreciation I felt and still feel for her care and time.

After three weeks at home, I returned to the hospital for a bronchoscopy to check for rejection. The procedure itself is not difficult when performed by an experienced professional. You are adequately sedated so that you don't really care and your throat is numbed so you feel nothing when the probe is threaded into your lungs for viewing. If your sedation is minimal, you may watch on the monitor as the camera moves around in your lung. During the examination, Dr. Iacono noted that the bronchi connection on the right lung was collapsing and not allowing full airflow through. It was decided to put in a stent to hold it open. These stents are very similar to the ones used in coronary arteries that are clogged. There was no pain involved, the procedure ended and I headed to recovery for an X-ray, some liquids and a thumbs up to head home. Total time involved was about four hours.

Next: **Becoming Normal Again.....**

GENE THERAPY and AAV

*From Applied Genetic Technologies Corporation website
www.agtc.com*

AGTC is developing a gene therapy product to treat Alpha-1. An investigator-sponsored Phase 1 Clinical Trial of an earlier (lower potency) version of the product was conducted at the University of Florida. The product was given to 12 patients and was well tolerated with no adverse events related to the treatment. A second, AGTC-sponsored Phase 1 Trial with a higher potency version of the product is in progress.

Gene Therapy is the introduction of genetic material into host cells with the goal of treating or curing disease. Many diseases are caused by “damaged” genes that result in a deficiency in an essential protein. Introducing the correct gene to the patient allows the patient's own body to produce the missing protein and treat the disease. AGTC's research efforts focus on the use of Adeno-Associated Virus (AAV) as the vehicle to deliver genes to human cells.

AAV is a small, stable virus that has never been shown to cause disease in humans even though the majority of the population has been exposed. The wild-type virus has only two genes and cannot replicate itself without helper functions provided by another virus. To produce a vector to treat a specific disease, the viral genes are removed and replaced with a specific therapeutic gene. In some cases a regulator, which can turn the protein expression on or off, and/or a promoter to

enhance expression of the protein in a specific tissue type, are also inserted into the virus.

AAV is an ideal virus to use as the vehicle for gene transfer because:

- AAV is a simple, easily manipulated virus
- AAV can deliver genes to both dividing and non-dividing cells
- AAV can deliver genes to a wide variety of tissue types from muscle to brain
- AAV has never been shown to cause disease
- AAV elicits only weak immunologic responses
- AAV allows expression of proteins in the host cells for long periods of time without integration into the host cell DNA.

Health Care Reform Bill

by Elinor Nuxoll

What is in the bill? The AARP Bulletin reports that by 2014 this legislation will extend affordable health insurance to 32 million uninsured Americans. It will provide subsidies for people with limited or moderate income, and prohibit insurers from denying coverage to people with preexisting medical conditions.

Provisions that take effect within a year include: banning insurers from cancelling or limiting coverage, providing tax credits to small businesses that offer coverage, providing temporary insurance (until 2014) for people who have been denied because of their health, allowing young people to stay on their parents' insurance until age 26, requiring insurers to use a high percentage of premiums for benefits instead of profits or overhead, and providing preventive measures, such as cancer screenings, free.

Basic Medicare benefits will be guaranteed, gradually closing the "doughnut hole" in prescription drug coverage, starting with a \$250 rebate this year. The cost of the bill will be paid by controlling fraud, abuse and waste in Medicare funds, by levying a new tax on the so-called "Cadillac" health plans, and higher taxes for wealthy taxpayers. According to the Congressional Budget Office, reform savings will also trim the federal deficit by \$143 billion through 2019.

Many uninsured people now wait for a crisis before they go to the Emergency Room, and by then some diseases may be in advanced stages. Health screenings and prompt treatment has the potential of saving thousands of dollars.

**Thank you for supporting Alphas
through the work of the
Alpha-1 Advocacy Alliance.**

Antibiotic Avelox and Liver Problems

The antibiotic Avelox may be linked to rare but dangerous liver problems. Bayer Inc., which makes the drug, is updating the product label to draw attention to this potential side-effect. Avelox is used to treat a broad spectrum of bacterial infections, including respiratory illnesses. But concerns raised in recent years in a variety of jurisdictions led Health Canada to investigate whether people taking the drug are at increased risk of liver injury. The generic name of the drug is moxifloxacin; it is in the quinolone class of antibiotics.

Health Canada says anyone who develops certain symptoms while on Avelox should stop taking the drug and contact their health care professional immediately. The symptoms are: abdominal pain, loss of appetite, yellowing of the skin and eyes, severe itching, dark urine, and pale-colored stools. Bayer updated the labeling for Avelox in Europe in the summer of 2007 and sent a "Dear Doctor" letter to European physicians to draw attention to the change in early 2008. That move followed a review of the safety data for the drug by the European Medicines Agency's Committee for Medical Products for Human Use.

Disease Prevention, Healthy Lifestyle May Add Years to Your Life

by Elinor Nuxoll

The February 2010 issue of A1AA Register reported the loss of two of our very special Alphas: William (Bill) H. Poplett, who loved to educate doctors about Alpha-1 and to talk about organ donation, and Pat Slavin, who developed the "Ask Pat" programs counseling and advising other Alphas for five years.

Thinking of these inspiring leaders, I wonder how I can help. As a homebound writer, and as a friend of an Alpha who lost his battle at age 47, I have researched and written articles on such subjects as flu, infusions, obstructive sleep apnea, and diabetes. I wrote about free screening offered by the AARP/Walgreen's Wellness Tour. I have written articles for

**A1AA Register is published by
Alpha-1 Advocacy Alliance, Inc.
Copyright © 2010 by
Alpha-1 Advocacy Alliance, Inc.
<http://www.alpha1advocacy.org>**

**For Information Call: 540-948-6777 or Toll Free:
1-866-FOR-A1AA;**

**Fax: 540-948-6763
PO BOX 202**

**(1-866-367-2122)
Wolfstown, VA 22748**

Disclaimer: All images, quotes, material are copyrighted by their original owners and are used in this newsletter strictly for the purpose of information and education and absolutely no financial profit, reproduced in complete compliance with US Code, Title 17, Copyrights, Chapter 1, Sec.107 on Fair Usage.

other publications on longevity, centenarians, nutrition, disease prevention and wellness.

I am reading a library book by the American Medical Association: *Complete Guide to Prevention and Wellness - What You Need to Know About Preventing Illness, Staying Healthy and Living Longer*. To live longer, many Alphas need an organ transplant. Staying healthy is important before and after the transplant.

My friend Kevin had been trying to get on the transplant list at the University of Washington Medical Center in Seattle. At 120 pounds he needed to gain more weight. He talked to the dietician on the Transplant Team, but his own efforts helped him begin to gain several pounds. Just eating a meal took so much effort, he began to eat six small meals a day.

The AMA book says, "Of all the steps you can take to stay healthy and prevent disease, eating a nutritious diet is probably the most important." Healthy eating can prepare you for transplant and recovery afterward. Then it can help you maintain a proper weight and lower your risk from some of the most common chronic diseases such as heart disease, cancer and diabetes.

Patient Enrolled in Study for Inhaled AAT

Kamada, a bio-pharmaceutical company engaged in developing, manufacturing and marketing specialty life-saving therapeutics, announced in early February that it has enrolled the first patient into its pivotal clinical trial with its new breakthrough compound of inhaled alpha-1 antitrypsin (AAT) delivered by an Investigational eFlow Nebulizer System (PARI Pharma GmbH), in patients with alpha-1 antitrypsin deficiency.

The Phase 2-3, multi-center, randomized, double-blind, placebo-controlled and international study will evaluate the efficacy and safety of inhaled, human AAT in alpha-1 deficient patients with emphysema. The trial will be conducted across several European countries. The study protocol has been designed in agreement with the EMEA under the product's orphan drug designation status.

Additionally, the FDA informed Kamada by letter in late March that the company will receive a response on approval of its ATT product, in the version administered intravenously, for the US market by July 1. The letter gives no information about actual approval of the product for sale in the United States, but it indicates that the answer will be positive.

Scientists Target

Genes to Alveolar Macrophages

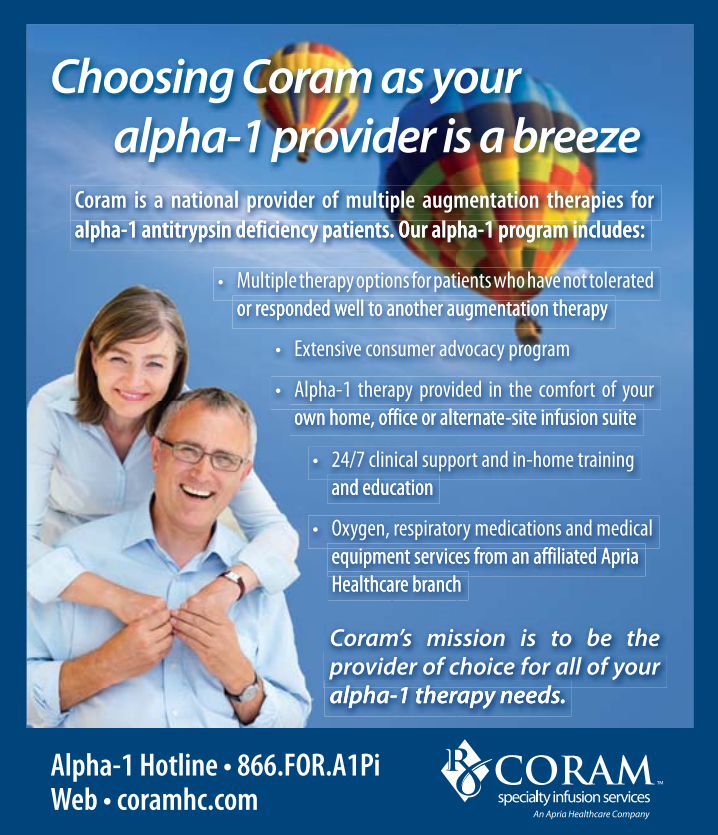
Previous attempts to correct single-gene defects that cause lung disease by gene transfer have failed to achieve sustained

gene expression in the mouse lung. However, researchers at Boston University School of Medicine developed an approach that enabled them to attain sustained *in vivo* expression of normal human alpha-1 antitrypsin at levels able to improve emphysema in mice. The scientists introduced gene-carrying lentiviral vectors into the windpipe of mice. They found that they selectively and efficiently transferred the genes they were carrying to resident cells known as alveolar macrophages. These cells were long-lived and continued to express the transferred genes for at least two years.

In a mouse model of emphysema, introduction into the windpipe of lentiviral vectors carrying the gene responsible for making normal human alpha-1 antitrypsin led to sustained alpha-1 antitrypsin expression in the lung and reduced disease. Therefore, the authors concluded that targeting genes to alveolar macrophages provides a way to achieve sustained gene expression in the lung and suggest that this might provide a therapeutic approach for overcoming overcome lung diseases caused by single-gene defects, for example emphysema caused by alpha-1 antitrypsin deficiency.

A1AA Online Fundraising Campaign

Now you can renew and order new magazine subscriptions online and help raise money for the Alpha-1 Advocacy Alliance. You can also invite your family and friends coast to coast to order their magazines too! They'll save up to 85% while our



Choosing Coram as your alpha-1 provider is a breeze

Coram is a national provider of multiple augmentation therapies for alpha-1 antitrypsin deficiency patients. Our alpha-1 program includes:

- Multiple therapy options for patients who have not tolerated or responded well to another augmentation therapy
- Extensive consumer advocacy program
- Alpha-1 therapy provided in the comfort of your own home, office or alternate-site infusion suite
- 24/7 clinical support and in-home training and education
- Oxygen, respiratory medications and medical equipment services from an affiliated Apria Healthcare branch

Coram's mission is to be the provider of choice for all of your alpha-1 therapy needs.

Alpha-1 Hotline • 866.FOR.A1Pi
Web • coramhc.com

CORAM
specialty infusion services
An Apria Healthcare Company

group keeps 40% of each purchase amount. When you encourage your friends and family to help, you could get 1 FREE movie ticket redeemable online!

Here's the web address to visit our fundraising site:

<http://www.magfundraising.com/>

Please share it with your friends, work colleagues and other potential supporters. If you have any questions email online@efundraising.com.

Thank you!

Shop at our Website



The Alpha-1 Advocacy Alliance Shoppe is located at <http://www.alpha1advocacy.org/frdonation.html>. While you are shopping for a T-shirt (design shown on the left), be sure to check out the

other items offered as fund-raisers. Also remember, when shopping online for ordinary items, be sure to go to the A1AA website and use the www.IGive.com and Giveline.com links to find those stores that give percentage (up to 25%) of your purchase dollars to your designated nonprofit organization.



Of course, our little buddy Alphapotamus can be purchased, too. Be sure to click on "full details here" and learn how Alphapotamus cheers up our little Alphas when they're in the hospital. Any purchase on the A1AA

Shoppe site helps the Alpha-1 Advocacy Alliance continue to fulfill its mission "to advocate for all individuals affected by Alpha-1 Antitrypsin Deficiency (Alpha-1) through programs and services of personal advocacy, education, support and public policy in order to improve all aspects of their lives."

If you're not a member of the A1AA, please go to <http://www.alpha1advocacy.org/membership.html> and join. It's a free membership and you'll get updates about A1AA programs, personal support, plus a copy of the bi-monthly newsletter. Thank you for your continued support and stay tuned for more announcements from the A1AA.

	Organ/Tissue Donor Card	
I wish to donate my organs and tissues. I wish to give:		
<input type="checkbox"/> any needed organs and tissues	<input type="checkbox"/> only the following organs and tissues:	
Donor Signature _____	Date _____	
Witness _____		
Witness _____		

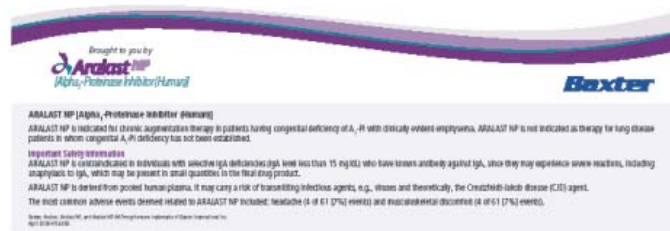


At last, encompassing Alpha-1 support just for you.

The ARALAST NP AATmosphere program provides Alpha-1 patients with assistance, support, education, and security.

- Insurance Assistance**
Helping research your benefits and explore options
 - One-on-One Support**
Providing therapy answers and personal advocacy
 - Knowledge Network**
Updating you on Alpha-1 research and information
 - Alpha-1 Security**
Offering resources and AAT augmentation therapy in the event of an insurance lapse*
- *For those who meet the program's requirements.

To learn more, visit www.aatmosphere.com or call 1-866-ARALAST (1-866-272-5278).



Caregivers

Caregivers are jewels who live amongst us helping make life easier for anyone who is not in optimal health or just young. Parents are caregivers forever and most spouses are as long as they remain married or able. Often times children, siblings, friends and significant others step up to the plate and serve in this role that can be draining, rewarding and fulfilling all at one time. Big shoes that only REAL people can fill.

From the family Caregiving 101 website, there are six stages for care givers.

1. Ask; You will need to ask questions of the doctors, home health nurses, physical therapists and at all appointments. Ask about all medicines being taken for your knowledge as you may be called upon to fill a weekly pill box. Ask about community assistance that may be available (cleaning, driving, sitting). In addition, you will need to ask if legal documents are in order- living will, advance directives, last wishes, and financial situation. As a parent, you must pay attention to financial security of trusts and funds for future care. Journal your findings.
2. Find; At this phase, you have been helping for 6 or more months. You need to find assistance to not only help you but relieve you. Utilize the social service programs available in the community to take breaks away. Find support groups for the illness, support groups for caregivers in your area. Find internet groups and email lists to participate in and exchange information. Search out more info

about the illness you are working with. Journal your resources.

3. Receive; Take the help offered to you through individuals, churches, home health agencies and relatives. Know your limits and respect them. Continue to explore the illness and its phases through support groups and systems. Journal your feelings.
4. Welcome; This is for the long term caregiver. Welcome the joys of your position, building a more intimate relationship through laughter and friendship with the recipient. Revive the personal relationship through dreams and conversations of the past. Forgive past issues. Journal your growth and hopes for the future.
5. Allow; Give yourself time to grieve and have sorrow. It's a process that does not happen quickly. Allow yourself to remember the good times together over the years. Reflect back on your caregiving knowing you gave it your all. Review your journal and examine how you have changed since your first entries.
6. Treasure; Treasure not just the memories, but the journey as well. Remember your dreams and ambitions and make those goals your next achievements. Share your experience through mentoring others or assisting in someone else's caregiving travels. Treasure your own personal growth and allow it to blossom.

FDA Says Competing Biologic Ads Both Misled

by Ben Comer online at Medical Marketing & Media

One is a sales aid, and one is a consumer brochure, but both ads—for CSL Behring's Zemaira and for Talecris' Prolastin—are false or misleading, FDA said in a pair of untitled letters.

The brochure for Prolastin minimized risks by featuring "multiple pages of easy to read benefit information...presented with large lettering and white spacing," in contrast to small font and blocked-format safety information "on the second to last page of a 12-page brochure," FDA's Office of Compliance and Biologics Quality (OCBQ) said in the letter. Additionally, the brochure made several claims related to improved lung function, which imply "a greater benefit for Prolastin-treated patients than is suggested by the PI, or by substantial evidence or substantial clinical experience," according to the letter.

The Zemaira sales aid made similar unsubstantiated claims related to lung condition and also used a comparative table—Prolastin vs. Zemaira—that wrongly positioned Zemaira as the "superior or more effective" treatment. The OCBQ letter pointed to a headline on the sales aid—"Unmatched purity. And peace of mind"—as a reinforcement of the misleading comparative claim.

Greg Healy, a spokesman for CSL Behring, stated that the company is "working with the FDA to address its concerns," and is no longer using the sales aid. Both CSL Behring

and Talecris were asked to "immediately cease the dissemination" of their respective materials, and to respond within ten business days regarding plans to comply with the request.

Remember to Shop at IGIVE.com

iGive.com is an Internet organization that allows you to designate your favorite charity as the beneficiary of your online shopping. The Alpha-1 Advocacy Alliance is one such charity that benefits. A penny a search and a portion of each purchase will be donated.



Register with **iGive** and shop at brand name online stores through the iGive Mall. Also, save money with exclusive coupons/free shipping deals. Plus, when you shop within 45 days of registering iGive will donate an extra \$5 to your cause! Over seven hundred (700+) member stores donate a percentage, ranging from 1% to 26%, of what you spend with them. This can add up to sizable donations for our group. You probably already shop at some of the stores, such as including Amazon.com, eBay, Staples, JCPenney, Barnes & Noble, Overstock.com, drugstore.com, Office Depot, Expedia, Home Depot, HSN, Best Buy, Drs. Foster & Smith, Gap, Buy.com, & NORDSTROM. For a complete list of stores, the percent donated and coupons, go to <http://www.igive.com/html/merchantlist2.cfm>.

Patient Enrolled in Phase 2b Study of L-CsA

PARI Pharma has enrolled the first patient in its Phase 2b clinical trial studying inhaled liposomal cyclosporine A (L-CsA) delivered via a customized Investigational eFlow Nebulizer System. The multinational study is investigating the safety and efficacy of PARI's L-CsA formulation. In previous clinical trials, reactions from physicians and lung transplant recipients to PARI's drug-device combination were encouraging. PARI Pharma's Phase 2b trial is a multi-center, randomized, double-blind, placebo controlled, parallel group, dose-finding study to investigate the safety and efficacy of L-CsA in doses of 10mg/day and 20mg/day to prevent bronchiolitis obliterans in recipients of lung transplants. Positive data regarding human lung deposition and distribution of L-CsA was published in the *Journal of Aerosol Medicine and Pulmonary Drug Delivery* last year and clinical, as well as preclinical data, will be presented in April at the Annual Meeting of the International Society of Heart and Lung Transplantation in Chicago.

Buy & Sell

Want to sell something? Need to buy something?
Call toll-free at 1-866-FOR-A1AA (1-866-367-2122)
to place your no-charge ad in the next issue.



Alpha-1 Advocacy Alliance
PO Box 202
Wolfstown, VA 22748

Address Service Requested

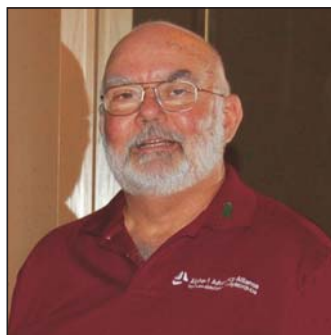
FOR INFO CALL: 540-948-6777
Toll Free: 1-866-FOR-A1AA
Fax #: 540-948-6763
<http://www.alpha1advocacy.org>

Inside: April Is National Organ Donor Month

THE ALPHA-1 FAMILY PROVIDING INFORMATION AND EDUCATION TO THE COMMUNITY.

Alphapotamus

On March 14, 2010, we lost another one of our hard-working, hard-playing, soft spoken Alphas, Carl Lynn Johnson. Carl hailed from Texas and felt extremely blessed to receive a double lung transplant in June of 2004 at Barnes Hospital in St. Louis. He had a strong religious faith and was so thankful for his gift of life. He regularly organized car shows to benefit organ donor awareness, showing his own beauty and treasure, a 1964 Galaxie. Carl volunteered to speak to groups about organ donation on a regular basis, always eager to share his story of diagnosis of Alpha-1 and his journey to transplant.



Carl, nearly three years post bilateral-lung transplant.

Carl volunteered to work on the Board of Directors of the Alpha-1 Advocacy Alliance from 2007-2009. He was there to mentor other Alphas who were newly diagnosed and those considering transplantation. He was always ready to hop on a plane or drive to a meeting and speak on

behalf of living with Alpha-1. His broad smile was always accompanied by a twinkle in his eyes. We at the A1AA are grateful for the time he spent with us.

Carl leaves behind his son, Carl Lynn, Jr. and his daughter, Kylie Marie Kulwicki. Donations in his memory may be made to the Texas Organ Sharing Alliance, 8122 Datapoint, Suite 200 San Antonio, Texas 78229

	Organ/Tissue Donor Card	
I wish to donate my organs and tissues. I wish to give:		
<input type="checkbox"/> any needed organs and tissues	<input type="checkbox"/> only the following organs and tissues:	
_____ Donor Signature _____ Date _____		
_____ Witness _____		
_____ Witness _____		