Lung Studies

A major research sponsor is the Alpha-1 Foundation, so called the “Alpha-1 Antitrypsin Deficiency Adult Clinical and Genetic Linkage Study.” It designed to learn about the natural history of liver disease in Alpha-1 and compare it with other individuals. Z2 Alpha-1 family members with ZZ Alpha-1 disease are enrolled in this study to determine the difference. This is a long-term observational study (no intervention is being tested) to help monitor the health and liver function. Many information will be collected over the course of the study to determine the relative risk of liver disease and to determine if the study can be terminated.

You must be an adult to join this study and, interestingly, you can’t have liver cancer. The leader of this study is Dr. John T. Thomas at Stony Brook University. In addition to this site, enrollment is also taking place at the University of California San Diego and Boston University. To learn more about this study, please contact Rosemary Nagy, the Study Coordinator at St. Louis University at (314) 977-9350 or rnagy@slu.edu. To find out more about this or other studies, please contact the Study Coordinator at St. Louis University. In addition to this site, enrollment is also taking place at the University of California San Diego and Boston University. To learn more about this study, please contact Rosemary Nagy, the Study Coordinator at St. Louis University at (314) 977-9350 or rnagy@slu.edu.

Alpha-1 Foundation

Community Calendars

To find out more about these or other events in your area, log on to  www.chp.edu/at_study  or call toll-free: 800-577-2638 • www.alphanet.org

Coral Gables, Florida 33134

COMMUNITY CALENDARS

- Alpha-1 Foundation headquarters at 3300 Ponce de Leon Boulevard, in Coral Gables, Florida

Story Ideas?

Do you have an interesting story that you think would make a great article for an upcoming issue of The AlphaNet? If so, please submit any ideas, comments and/or suggestions to Christine Lassen at cllassen@alphanet.org.

AlphaNet Celebrates 20 Years of “Alphas Serving Alphas”

AlphaNet has reached a major milestone: Twenty Years of Alpha Serving Alphas. Since its founding in 1995, AlphaNet has been at the forefront of providing health management and educational resources. Over the twenty years, this commitment to serving the Alpha-1 community with a focus on education, advocacy and long-term care has led to major improvements in the care and treatment of Alpha-1 disease. Today, AlphaNet works every day to improve the quality of life for individuals with Alpha-1 disease and their families. We do this by educating them about the disease and connecting them with a supportive community of peers who understand the unique challenges of living with Alpha-1 disease.

AlphaNet has also played a key role in advancing research to find a cure for Alpha-1 disease. Through the support of our members, AlphaNet has been able to fund numerous studies and clinical trials that have led to new therapies and treatments for Alpha-1 disease. We continue to invest in research that will ultimately lead to better outcomes for individuals with Alpha-1 disease.

AlphaNet is grateful to all of our members for their continued support and dedication to helping others. We look forward to serving you for another 20 years and beyond.

May-June 2015

For Your Information...

Your AlphaNet Coordinator is a great resource, whether you are a newly-diagnosed Alpha or a long-time AlphaNet subscriber.

Check out the “Questions to Ask Your Coordinator” (template) and other FAQs at www.alphanet.org.

July 24-26 – National Education Conference

Garden Grove, CA

To find out more about conferences and support groups, visit our website at www.alphanet.org or call toll-free: (888) 825-7421, ext. 233.

Alpha-1 Foundation Events Calendar

August 9 – Step Forward for Alpha-1 Walk

Littleton, CO

August 25 – Escape to the Cape Bike Trek

Cape Cod, MA

To find out more about these or other events in your area, log on to www.alphanet.org or call toll-free: (888) 825-7421, ext. 233.

Alpha-1 Foundation

Education Days

July 24-26 – National Education Conference

Garden Grove, CA

September 19

Cleveland, OH

November 7

Orlando, FL

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AlphaNet maintains a list of Alpha-1 disease support groups throughout the United States and Canada. For the Coordinators who have worked for AlphaNet since its inception, this 20th anniversary bears special significance, as working for AlphaNet has been an integral part of their lives. As Dr. Charles M. King, who has been employed by UNESCO for 20 years, describes it, “I have always felt privileged to work for UNESCO, where I have had the opportunity to make a difference in the world.”

One of the most significant achievements that AlphaNet has accomplished in the past twenty years has been its successful partnerships with all three pharmaceutical companies that manufacture Alpha-1-related therapeutics. This means that AlphaNet can now work with any of these companies to identify the best therapies for their Alpha-1 patients.

As part of our mission, AlphaNet is committed to supporting research for a cure, as well as providing funding for educational and clinical research programs for the Alpha-1 community. Issues in inception, AlphaNet’s cumulatives contributions to the Alpha-1 Foundation has raised over $45 million. "We continually strive to find new ways to increase AlphaNet's contributions to the Alpha-1 Foundation," CEO Robert C. Bennett said.

Ultimately, we look forward to fulfilling our Alpha Serving Alpha for the next twenty years to come.

What Alpha-1 Research Studies Are Currently Enrolling?

People with Alpha-1 Antitrypsin Deficiency, or Alpha-1 disease, are often asked about research studies that they can volunteer to join. There are a number of research studies currently looking for participants and several are open on the website that might be of interest. Remember that each study has its own criteria for participation and contact information. There may be additional criteria that apply to certain studies.

To find out more about the study that might be of interest, contact the study site, which can give you the latest information and answer any questions.

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**Clinical Corner**

By: Teresa Kitchen, BSN, RN, AlphaNet Clinical Nurse Manager

**Essential Dietary Guidelines for Alpha-1 Patients**

- **Calcium**
  - Calcium works with magnesium to regulate lung function, muscle contraction and blood clotting. It also plays an essential role in the function of the nervous system.

- **Read labels and ingredients on all foods. Avoid those that contain high sodium levels.**

- **Sodium**
  - An excess amount of sodium chloride, a common table salt, can cause fluid retention (also called edema), increased blood pressure and shortness of breath. If your doctor asks you to reduce your sodium, follow these guidelines:
    - **Alpha-1** patients who are on supplemental oxygen therapy may dry your mucus membranes and cause irritation. Fluids keep you hydrated.

- **Fluids**
  - Fluids are important because they play an essential role in protecting the body. Producers add water to rinse out coating to fight infection.

- **Bladder**
  - Drink enough fluids is essential for the flushing and clearance of your pulmonary secretions. Also, supplemental oxygen therapy may dry your mucous membranes and cause irritation. Fluids keep you hydrated.

- **Sodium**
  - Sodium is necessary for proper body function. However, we will discuss only a few that are especially significant to those with lung disease. Also, it is important to note that some medications for lung disease may have sodium in them. You should consult with your doctor or diettitian about possible interactions with the specific medications you are taking.

**Protein**

- **Protein is important because it plays an essential role in protecting the body. It produces antibodies to fight infection.**

**Did You Know...**

- **Alpha Cycles His Way to Improved Health**
  - Miles’ perseverance and devotion to cycling is certainly something that we can all aspire to! "I am a competitive person and want to accomplish all that I possibly can. With that being said, I added distance to my ride every time I reached the point where I felt content." Miles started his new workout schedule with a low mileage ride every morning after he returned home from working the night shift at the coal mine. From there, the numbers went riding distance and Miles began to feel stronger.

**Alpha Ben Miles from Westfield, Alabama has found that his passion for cycling has led him to better overall health. Miles, who has worked in an underground coal mine for 33 years, began experiencing difficulties with his lungs a few years ago.**

- **Lead**
  - Lead is a heavy metal that is found in paint, dust, batteries and some types of pottery. The metal can be harmful to the body, including the central nervous system.

**Calcium**

- **Calcium works with magnesium to regulate lung function, muscle contraction and blood clotting. It also plays an essential role in the function of the nervous system.**

**Osteoporosis, or "porous bones," affects more than 25 million women and six million men in the U.S. It is very common in people with COPD and even worse if you are taking corticosteroids.**

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Kamada Inhaled Study

Alphas seem very interested in whether an inhaled version of augmentation therapy might be available soon. One way to help evaluate inhaled therapy is to participate in a study being performed at two sites in the U.S. This study is being sponsored by Kamada and is a double-blind, placebo controlled trial. Patients already receiving intravenous augmentation therapy will have to stop this treatment for 8 weeks prior to the study and during the entire time of participation in the study. If you decide to join this study, you will receive a bronchoscopy at the beginning and again after 12 weeks on either placebo inhalations, or one of two different doses of inhaled augmentation therapy. At the end of the blinded portion of the study, participants may elect to continue into a 12-week open label portion during which everyone will receive the highest dose inhaled alpha-1 antitrypsin. To learn more about this study, contact Joanna Nolte in Gainesville, FL at (352)273-7225 or noltej@ufl.edu; or contact Dr. James Stocks in Tyler, TX at james.stocks@uthct.edu.
The PELICAN Study

Frequently asked questions

What is PELICAN?
Peer-led O₂ infoline for patients and caregivers (PELICAN) is a research program that aims to improve the health and wellbeing of people with COPD and their caregivers.

Who can participate?
PELICAN may be for you if…
- You are an adult (over 18 years old)
- You have COPD and are using oxygen 24hrs/day

What procedures are involved in PELICAN?
The study will take place at your home:
- You will be given written material, which you can read at home, at your own pace
- Phone calls will be made to your home
- You will be compensated for your participation.

Interested?
- From your home, call toll-free a PELICAN study staff member at (844) 627-5587.
  Hours: M-F, 7:30 AM – 6:30 PM (Central Time)

We hope you join PELICAN!