Help us study the ‘bugs in your lower airways’

This edition carries with it an insert inviting you to understand and participate in the GRADS research study of the NIH National Heart Lung and Blood Institute. You will likely hear much more about GRADS over the coming years; however, this introduction is meant to stimulate 50 PiZZ Alphas who are not on augmentation therapy to participate in this study by calling the closest GRADS center (ZZ Alphas who are on augmentation therapy will also be included – but they are easier to find). The goal of the study is to better understand the lung microbiome – the cumulative collection of “germs” in our body, or in this case, the microscopic ‘bugs that inhabit the lower airways.’

Many of the major medical centers participating in the GRADS program have not been CRC clinics for the Alpha-1 community. This is an opportunity to expand the number of physicians who know a lot about Alpha-1. It will happen if you can educate them about Alpha-1 as much as they can educate you about why the Alpha-1 community should participate in understanding the bacteria, mycobacteria (germs similar to tuberculosis), and viruses that live in our bodies.

Thank you for being a member of the Registry. I know the many questionnaires that we send out take your time and willingness to execute. However, every research study done in Alpha-1 helps keep this rare disease in the headlights of the larger COPD and liver disease communities and the pharmaceutical manufacturers that are instrumental in getting new therapies through the “valley of death” from which many new drugs and therapies do not emerge. And many of these questionnaire projects show very interesting findings – such as the one reported in this edition by Kristen Holm, PhD.

When you come to the Alpha-1 Education Days that are jointly sponsored by the Alpha-1 Association and the Alpha-1 Foundation, I hope you’ll introduce yourselves to me and to my staff. And please invite your family members and Alpha-1 friends to join the Registry to hear about research studies offered.

Sincerely,
Charlie Strange, MD
Director, Alpha-1 Foundation Research Registry and ACT Study
Clinical Resource Center:

Boston Medical Center leads with ‘open source biology’

By Andrew Wilson, MD and Darrell Kotton, MD, Boston University Alpha-1 Center

Boston Medical Center and The Boston University Pulmonary Center have long-standing ties to the Alpha-1 community through Gordon Snider, MD, the first chief of pulmonary medicine at our institution and a seminal clinician, teacher and researcher in the field.

Snider’s work demonstrating the role of neutrophil elastase in the pathogenesis of emphysema, and interest in the role of alpha-1 antitrypsin (AAT) in protecting the lung against it, created a legacy that lives on today in the form of the Alpha-1 center at Boston University. In 2004, we (doctors Wilson and Kotton) began working on a project to develop a gene therapy for Alpha-1 Antitrypsin Deficiency. Neither of us had a special interest in Alpha-1 at the time, and we had no idea back then that Alpha-1 and the Alpha-1 community would become a focal point in our research and clinical lives.

Since then, of course, much has changed. First, great advances have been made in our scientific areas of interest — gene therapy and stem cell biology — which have made their clinical relevance more immediate and obvious than ever before. Gene therapy studies for Alpha-1 and other diseases have advanced to human clinical trials and demonstrated the ability to restore normal gene function, and in some cases cure disease.

Second, the discovery of induced pluripotent stem cells (iPSCs) in 2006, one of the most important scientific discoveries of our time, has given us a new platform to examine Alpha-1. These cells, which can be created from adult patients but have properties similar to embryonic stem cells, have allowed us to study Alpha-1 using patient-derived cells.

This has allowed us to study Alpha-1 in a dish using iPSCs created from Alpha-1 PiZZ patients at Boston Medical Center, and to ask questions about how the disease works, what treatments might be effective, and how one patient’s disease differs from another despite having the same genetic mutation.

In 2010, we published the first derivation of iPSCs from patients with lung disease, including PiZZ Alpha-1 Antitrypsin Deficiency. We have made more than 100 of these cell lines available, free of charge, to the academic research community through a philosophy and approach we term ‘Open Source Biology.’ Our Alpha-1-related projects currently use our PiZZ iPS cell lines to engineer new liver and lung tissues, the two lineages most affected by Alpha-1.

We have published tissue-engineering approaches for deriving bioartificial lungs that can be functionally transplanted into rodents, and we are working to adapt these approaches to engineer transplantable human bioartificial lungs from our banked PiZZ iPSC cell lines.

As the Alpha-1 focus of our research program grew, it became clear to us that something important was missing: patients! This realization lead to the inception in 2010 of the Alpha-1 center, an entity that includes both our laboratories for the local Alpha-1 support group. We have been active members of the Alpha-1 community, participating in regional and national Alpha-1 Association education days and in numerous Alpha-1 Foundation events.

In 2010, Dr. Kotton, co-director of both the Boston University Center for Regenerative Medicine and the Alpha-1 Clinical Resource Center, was awarded the Alpha-1 Foundation’s prestigious Celtic Connection Shillelagh, an annual award given to the individual who has most impacted Alpha-1 research or care.

You can meet our clinical team and contact the Alpha-1 Center at Boston Medical Center through our website www.alpha-1center.org or by calling (617) 638-7480.
Stem cells have great promise to treat diseases in the future

But not yet. So beware offers of stem cell lung treatment

By Darrell Kotten, MD
Associate professor,
Boston University
Co-director, Alpha-1 Center

How long will it be until stem cells are available to treat Alphas? Should I sign up for a stem cell trial for emphysema, even if this means traveling to another country and paying out of pocket? Despite the promise of stem cells to regrow new lung tissue and intense laboratory research to develop stem cell therapies for Alphas, no type of human stem cell to date has any published proof that these cells can stop the progression of emphysema or regenerate lung tissue. We and others are focused in the laboratory on engineering various stem cells and testing to see if they can rescue damaged lungs or serve as gene therapy vehicles for Alphas.

However, most scientists agree that stem cell-based approaches to treat lung disease are still highly experimental and too dangerous to try in human subjects. We still need time to optimize our methods, and to test the safety of the cells.

We have great hope that our approaches will be ready for application in the near future. Our laboratory has been focusing on developing delivery devices engineered from bone marrow stromal cells. The intent of investigators conducting these early trials using MSCs is not to regenerate lung tissue, or to use the cells as lung stem cells. Instead, investigators hope that these cells might reduce inflammation in the lungs.

The bottom line on stem cell treatments for Alphas is that the science is progressing rapidly, but not fast enough to be used clinically in humans yet. Therefore, any advertisements or promises from offshore clinics charging money for “stem cell treatments” for Alphas or other patients with emphysema should be viewed with extreme caution. A useful resource for those considering stem cell treatments, and its goal is to educate patients about the promise and perils of stem cell clinical trials. It provides a basic list of questions to ask or look up before participating in any stem cell trials claiming efficacy for patients, particularly when the investigators are charging patients to participate:

http://www.closerlookatstemcells.org

Other information of potential interest:
http://www.who.edu/stemcells
http://www.kottenlab.com
http://www.bu.edu/alpha-1/

Comments from the ACT survey (see page 11):
“This was a win-win. I got to find out more about my own genotype and about Alpha-1 in general, and you guys got valuable research data. I especially appreciated the confidentiality. Great experience – would recommend it. Thanks.”

Q: What are PFTs?
A: Pulmonary Function Tests, or PFTs, include a group of tests that measure how well your lungs work. These tests can be used to measure several things, including how much air you can move in and out of your lungs, how quickly you can move that air, how much air is in your lungs, and how well your lungs absorb oxygen from the air you breathe.

Q: What are PFTs good for?
A: While there are other reasons for getting PFTs, the most common reason for getting PFTs for someone with Alpha-1 is to get a measure of lung function (like the FEV1) and to follow it over time. This helps your doctor understand how well your lungs work and if they are changing.

Q: I see different headings listed on my PFT report. What are they?
A: There are a number of different types of breathing tests that are performed as a part of PFTs. Some of these include:

* **Spirometry:** Spirometry is the most common breathing test performed. It can be measured as a part of comprehensive PFTs, using the computerized equipment in a pulmonary function lab, but spirometry is also sometimes performed on its own, with a handheld device.

To measure spirometry, you start with several normal breaths, then take the deepest breath you can before blowing your lungs out. Lung volume testing measures the amount of air in your lungs, which can be either increased or decreased in different types of disease. There are a number of different parameters that can be measured as a part of measuring lung volumes, and some of them can be abnormal in patients with Alpha-1, particularly if you have chronic obstructive pulmonary disease (COPD).

**Diffusing capacity:** Once air gets into your lungs, one of the most important things your lungs do is absorb oxygen to deliver throughout your body. The diffusing capacity (often referred to as the DlCO) measures how efficiently oxygen is passed from your lungs into your blood. It can be low in COPD and in some other lung diseases.

Q: What do I need to know?
A: After reaching adulthood, everyone’s lung function declines gradually with age. Several conditions can cause the FEV1 to decline faster than normal, including smoking and Alpha-1. Tracking the rate of decline of FEV1 is one common reason that doctors track PFTs in their Alpha-1 patients, even if they have normal lung function to start with. For those on augmentation therapy, the goal is to return the rate of FEV1 decline to normal.

Lung volumes: Even after you breathe out completely, some air remains in your lungs. Lung volume testing measures the amount of air in your lungs, which can be either increased or decreased in different types of disease. There are a number of different parameters that can be measured as a part of measuring lung volumes, and some of them can be abnormal in patients with Alpha-1, particularly if you have chronic obstructive pulmonary disease (COPD).
GRADS Study: Why are some Alphas sicker than others?

By Mary Brooks
Research Program Assistant

The University of Pittsburgh has received a grant from the National Institute of Health’s National Heart, Lung, and Blood Institute (NHLBI) to fund the Genomic Research in Alpha-1 Antitrypsin Deficiency and Sarcoidosis (GRADS) study.

Its purpose is to study the microorganisms or ‘bugs’ present in the lower airways of individuals with Alpha-1 and sarcoidosis to determine whether these germs affect the severity of these diseases. Some Alphas with lung disease get much sicker than others, and this study may help us understand why.

Microorganisms inhabit the lungs of every human being, however, the GRADS investigators suspect those with Alpha-1 host specific microorganisms that contribute to their disease symptoms. A better understanding of these microorganisms could help doctors and researchers develop treatments for Alpha-1. In the coming months, these investigators will begin recruiting individuals with ZZ and mZ genotypes to participate in this exciting study.

Both smokers and never-smokers needed to study Alpha-1 lung blood vessels

Columbia University is conducting a study sponsored by the Alpha-1 Foundation to look at what changes, if any, occur in the blood vessels of the lungs of patients with Alpha-1. The goals are to use the information gained from this study to possibly develop new treatments for Alpha-1. Participants are asked to travel to Columbia University Medical Center and have a CT scan of their chest and MRI of their heart and lungs. The entire study visit will take about 5-7 hours; reimbursement is available.

To be eligible for participation, you must be 40-80 years old, have an Alpha-1 genotype of either PIZZ (on or off augmentation therapy) or PIMZ, and be able to undergo the study procedures. Why should you participate?

The only way to develop new treatments and therapies for Alpha-1 is to study Alphas with disease. The more that we understand about the changes that occur in the body, the more we will be able to effectively treat these changes.

If you would like to participate or for more information, call Columbia University at (212) 342-4162 and ask about the MESA-COPD/ALPHA-1 Study.

Alpha-1 Foundation welcomes newest CRCs – and more coming

By Kathy Welch
Manager, program administration, Alpha-1 Foundation

The Alpha-1 Foundation is committed to aid patients by providing greater access to physicians with Alpha-1 expertise, and by funding research to find better treatments and a cure for Alpha-1. To that end, the Foundation has expanded the network of Clinical Resource Centers (CRCs) throughout North America. It now includes more than 110 physicians specializing in the care and treatment of Alphas. There are 77 CRCs in 30 states and the province of Ontario, Canada, treating more than 4,000 patients.

Since 2012, the Foundation’s CRC network has grown significantly, with the addition of 20 new sites. Among them are four states or provinces that did not previously have a CRC. Georgia, Indiana, Nevada and Ontario. The Foundation’s aim is to have a CRC in every state, and we expect to add more in 2013.

These “Alpha Docs” are a valuable component in providing improved healthcare and increased detection for Alpha-1. The CRC network includes academic centers, research laboratories and clinical settings with a focus or expertise in Alpha-1. Some physicians specialize in treating lung disease, while others specialize in liver disease. Many sites have resources for Alphas, such as support groups, pulmonary rehabilitation and organ transplant programs. All CRCs (and their patients) have access to the Alpha-1 Association’s genetic counselor, Sara Wierne, LCPC by calling the toll free number 1-800-785-3177.

A site wishing to be designated a CRC must complete an application process which is reviewed by a panel chaired by the Foundation’s clinical director. The basic criteria for designation as a CRC are an explicit interest in Alpha-1 research and the care and treatment of Alpha-1 patients, and at least seven Alpha-1 patients currently seen in practice. The site must provide the credentials of all physicians who will be seeing Alpha-1 patients.

You can find an Alpha-1 specialist by visiting the Alpha-1 Foundation website, www.alpha-1foundation.org or call (877) 228-7321, Ext. 269.
An Alpha call to action

‘Get involved,’ says the 4,000th member of the Research Registry

By Deirdre Walker
Registry Coordinator

Since coming to work for the Alpha-1 Foundation Research Registry in November 2012, it has been my pleasure to become acquainted with an amazing community of Alphas. One of our success stories has been that the Registry has reached over 4,000 participants.

Casey Wolff from Naples, FL, is our 4,000th participant and he agreed to share his story for the Registry Update. His enthusiasm for Alpha-1 research and desire to motivate everyone into action brings to mind these words of Martin Luther King Jr. ‘If you can’t fly, then run, if you can’t run, then walk, if you can’t walk, then crawl, but whatever you do, you have to keep moving forward.’

He has a suggestion for all of the Alphas out there: “Get involved.” And he has some ideas how to do that.

Wolff’s diagnosis was similar to the stories of many other Alphas. It took five years for his pulmonologist to realize that he needed to be tested for Alpha-1. Even though the diagnosis was delayed, Wolff’s reaction was not.

Shortly after the diagnosis, Wolff attended his first Alpha-1 Education Day in Gainesville, FL. There, he made it a point to meet everyone he could. He decided to get involved with the Research Registry and immediately signed up for a study now being conducted by Michael Campos, MD. He plans to sign up for any study that can use him in the search for a cure.

“Had trouble filling the circles with enough blood.”

He encourages all Alphas to pay attention to the Alpha-1 Association’s advocacy updates and to engage their member of Congress on the legislation most relevant to Alpha-1. By simply expressing your opinion on legislation, you can have a positive impact on any outcome, he says. The Association’s grassroots advocacy program is a great place to find information on advocating public policy and the issues that affect the Alpha-1 community, while also being a way to make your voice heard.

Get your medical community involved:

Raise awareness with your doctors and nurses, and make others aware of Alpha-1. Anyone who gets involved with the Alpha-1 community hears many stories about the frustration Alphas have in dealing with doctors who didn’t consider testing for Alpha-1, and how their Alpha-1 diagnosis took years longer than it should have.

Keep learning:

Wolff urges everyone to go to Alpha-1 education days and other Alpha-1 events. As he says, “It’s a great way to stay in touch with what’s going on in the Alpha-1 world and to keep the focus on finding a cure.

Help fund a cure:

Even for those members of the Research Registry who are nervous about certain research studies (please remember that some studies only require answering a questionnaire!), helping to raise funds for research is a great way that you can keep the search for the cure moving forward.

Building Friends for a Cure, the Alpha-1 Foundation program, was created to help the community raise funds for Alpha-1 Research. For information and help with a Building Friends for a Cure event, contact Angela McBride, director of community relations and development for the Foundation, at (877) 228-7321 or are@alpha-1foundation.org.

There are many ways to make a difference; you just have to go out and find what works for you. Thank you for being a member of the Alpha-1 Foundation Research Registry!

Chocolate cake and the S allele

By Sara Wienke, MS, LCGC
Program director, Alpha-1 Association Genetic Counseling Program

In genetics, an allele simply means a different form of a gene. If we think of our genes as recipes for proteins, an allele is a different recipe. For example, there is more than one recipe for chocolate cake, and some are better than others.

There are three common alleles for alpha-1 antitrypsin (AAT). The “normal” allele is designated M. This version of the gene is a recipe for an alpha-1 antitrypsin protein that is made in the liver, folds properly, travels through the bloodstream and serves to protect the lungs from damage.

The most common alleles that lead to the deficiency of alpha-1 antitrypsin are the S and Z. We often hear about the Z allele, but not as much about the S allele. We all carry two alleles or copies of the gene for Alpha-1. We inherit one allele from our mother and the other from our father. In the United States, it is estimated that 2-3% of people are carriers for the Z allele, meaning that they are MZ. It is estimated that 3-8% of people in America are carriers of the S allele and therefore MS. The S allele is more common, but it seems that most people know less about it.

The Z allele is a recipe for an AAT protein that actually folds incorrectly and cannot escape the liver. The Z protein forms polymers, or long strings of Z protein that remain inside the liver cells where they are made. As a result, some Alphas with the Z allele can have liver damage.

Since most of the Z protein does not travel to the lungs, it is unable to protect the lungs the way the M protein does. In contrast, the S allele is a recipe that makes alpha-1 protein that is less stable and gets destroyed by the body faster. Since it does not get trapped in the liver like the Z allele, the S allele does not carry the same risk for liver disease. People that are SS have about 60% of the normal amount of alpha-1 antitrypsin in their blood. They are therefore not as deficient as individuals that are ZZ, who have about 15% of the normal amount of alpha-1 antitrypsin in their blood.

One question that many people ask is, “what are the risks to someone that has the S allele?” The answer is that it depends on what other allele they have. For individuals who are SZ, the risks for lung disease are present, but not quite as high as the risks associated with being ZZ. However, the risks for liver disease would be the same as an ZZ (an infrequent occurrence). Individuals who are SS have levels of AAT in their blood that are slightly higher than individuals who are MZ, therefore their risk for pulmonary disease is similarly low and rarely found unless the SS person is a smoker.

Since they do not have a Z allele, SS individuals are not at increased risk for liver disease above the general population. Individuals who are MS have alpha-1 antitrypsin levels that are essentially normal and should have no increased risk for lung or liver disease. They can, however, pass the S allele on to their children. It is important for parents to know in order to accurately assess the risk to future generations and other members of the family.

While 95% of deficiency alleles are S or Z, there are other more rare alleles, which include null alleles. Null alleles do not make any alpha-1 antitrypsin protein at all – and therefore do not increase risk for liver disease, but they can greatly increase the risk for developing lung disease. If you or a family member carries a rare allele, I encourage you to call the Alpha-1 Genetic Counseling Center at 1-800-785-5177 with questions about your specific health risks and testing for these alleles.

Comments from the ACT survey (see page 11):

“My experience has been great and everyone I have talked to has been extremely helpful and solved the problem quickly.”

“I was confused. I think it was the wording. I was genotyped as MS, but had to read the letter a couple of times to realize I am a carrier. It could just be me!”

“As a nurse, I still found the results letter a little confusing. I think it was the wording. I was genotyped as MS, but had to read the letter a couple of times to realize I am a carrier. I thought I’d be lost.”

“Here’s a research effort that provides a unique public service at no charge to those who avail themselves of the opportunity. What’s to complain?”

“More information about being a carrier of Z would be helpful.”
Marriage, relationships are good for an Alpha’s health

Thanks to you, survey of Alphas with lung disease taught us a lot

By Kristen Holm, PhD, National Jewish Health, Denver, CO

As members of the Alpha-1 Foundation Research Registry, you have been very generous in sharing your time and experiences to support research studies.

One example of this generosity is your response to a study conducted from 2008 to 2010. It focused on Alphas who have developed chronic obstructive pulmonary disease (COPD), which includes emphysema and chronic bronchitis.

To all who participated in this study, thank you so much! A survey was mailed to Registry members with COPD in January each year from 2008 to 2010. More than 600 people returned the first survey, and more than 370 people returned all three surveys. This is a wonderful response, and I appreciate all the time you devoted to completing these surveys.

The surveys asked about many aspects of your life, including quality of life, shortness of breath and symptoms of depression and anxiety. These comprehensive surveys allow the research team to answer many different questions with the information you provided. At this point, five articles based on this survey have been accepted for publication in scientific journals. These articles inform medical professionals about the experiences of Alphas with lung disease and we hope they will stimulate more interest in and attention to your experiences.

One of the unique things about Alphas is your wide age range. For this study, I was interested in learning whether younger Alphas have more difficulty living with lung disease than older Alphas. I assumed younger Alphas would have more difficulty, because they would be less likely to expect a chronic health problem in their lives, and also might be juggling a hectic life with work and family responsibilities. One of the published articles listed below specifically looked at whether younger Alphas report worse quality of life, more shortness of breath, and more symptoms of depression and anxiety.

As it turns out, relationship status makes a big difference. Among people who were married or in a committed relationship, younger Alphas did not report more depression or shortness of breath, or worse quality of life. Among people who were single, however, younger Alphas did report more depression and shortness of breath. They also reported worse quality of life.

Younger Alphas also reported more anxiety, regardless of their relationship status. These results suggest that social support may be very important for younger Alphas with lung disease. For all Alphas who are single, other sources of support may be important — and should be looked at in future research studies. Future research should also focus on identifying the unique concerns of young Alphas with lung disease, particularly those who are single.

As you can see, findings from this study lead to more questions about the experiences of Alphas.

There is still information from the survey that has not been looked at yet, and we plan to continue using the information to learn more about your experiences living with lung disease.

Articles based on this study


Your SatisfACTion is Our Top Priority

By Laura Schwarz, ACT Study Coordinator

Here at the Medical University of South Carolina in Charleston, the Alpha-1 Coded Testing (ACT) Study team is busy every day. We assist you by phone and email with test kit orders and questions about Alpha-1. If you request a test kit, we respond by checking and entering your information into our ACT database, packing and shipping your ACT kits, opening your returned blood samples to remove your identity and to make sure there is a sufficient amount of blood on the card, and, if so, shipping them overnight to the Alpha-1 lab of Mark Brantly, MD, at the University of Florida.

In a few days, an overnight shipment arrives here, this time with your test results enclosed. The code on these results is matched to your code in our secure database where your name and address are located. At that point, your result letter is printed and mailed to you. The next week we start all over again!

Every couple of months, we email a “satisfaction survey” to a random group of ACT participants to get feedback on our efforts. We would like to share the results of the seven survey questions we asked, with replies from 176 participants, between 2011 and 2013, to see how we are doing.

Was your request handled in a timely manner?

Typically, once a participant has completed the online consent form and questionnaire, the kit is sent within two weeks. If the participant requested a paper consent and questionnaire, the process takes longer, due to mailing the forms, receiving them back, and then mailing the kit. We mail approximately 200 kits per month and have one person packing them.

How would you rate the ability of the research staff to answer the questions you had?

Our staff is willing and able to answer participant questions regarding the ACT Study. If we can’t, we will find the answer and return the call or email. The chart shows our ratings.

How would you rate the expertise of the research staff in discussing Alpha-1?

In-depth Alpha-1 and genetics questions are forwarded to our genetic counselor. Sara Wienieker, offers free counseling advice and can be reached through her toll-free number, 800-785-3177.

How would you rate the ease of completing the testing?

We are pleased with the success of our online forms, but certainly understand the necessity of paper forms and continue to provide them as a last resort.

As for the test kits, two lancets are mailed with the testing kit, which is sufficient for most people. However, if a blood card is returned without all three circles filled, we return it with more lancets so the participant can add more blood to his or her card. The lab cannot provide an Alpha-1 level if the card doesn’t have enough blood on it.

What is your opinion of offering the consent and questionnaire in an electronic format only? (Please comment below if you do not support this initiative.)

Please note that this question was included in the survey before we began offering paper forms. We have found that most of our participants support the online forms.

How would you rate your overall satisfaction with the ACT Study?

Since the ACT Study is an ongoing project, we are proud to see that most of our participants are satisfied. There will always be a few individuals whose lancets break or whose kits are delayed, but we are committed to keeping such mishaps to a minimum.

Some participants added comments to their survey questions. You can read a few of them scattered through this newsletter, under the heading “Comments from the ACT survey.”
Alpha-1 Foundation
The Alpha-1 Foundation is dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1). The Alpha-1 Foundation has invested nearly $47 million to support Alpha-1 Antrypsin Deficiency research at 94 institutions in North America, Europe, the Middle East and Australia.

Alpha-1 Association
The Alpha-1 Association is a member-based not-for-profit organization founded in 1991 to identify those affected by Alpha-1 Antitrypsin Deficiency and to improve the quality of their lives through support, education and advocacy. The Association has a network of more than 75 volunteer-led support groups around the U.S.

AlphaNet
AlphaNet, Inc. is a unique disease management organization. Through its medical and operations staff, AlphaNet provides a wide range of integrated support services to individuals with Alpha-1 Antitrypsin Deficiency who require augmentation therapy, oversees and sponsors clinical trials involving Alpha-1 therapies, and makes available a comprehensive disease management and prevention program to improve the quality of life of those affected by Alpha-1.

The Registry Update is funded by unrestricted educational grants from CSL Behring
Centric Health Resources
Grifols

Calendar 2013

Sept. 25 Greenwich Country Club Alpha-1 Golf Tournament Greenwich, CT Kenneth Irvine ken.irvine@scotiabank.com
Sept. 26-29 Team Alpha-1 Escape to the Cape Bike Trek Cape Cod, MA Angela McBride amcbride@alpha-1foundation.org
Sept. 28 Get the Scoop on Alpha-1 Fairmont, MN Julie Liljenquist tjilji@midco.net
Oct. 12 Team Alpha-1 Walk South Bend, IN Terri Nickerson canary.terry@live.com
Oct. 19 Education Day Charlotte, NC Alexis Artiles aartiles@alpha1.org
Oct. 20 Team Alpha-1 Walk Santa Monica, CA Ken Benson kenneth.benson@sbcglobal.net
Oct. 26 Team Alpha-1 Walk Chicago, IL Angela McBride amcbride@alpha-1foundation.org
Nov. 9 Step Forward for Alpha-1 Walk West Palm Beach, FL Gordon Cadwgan gcadwgan@comcast.net
Nov. 16 Education Day Anaheim, CA Alexis Artiles aartiles@alpha1.org
Ongoing Cans for a Cure - Recycling Initiative Mercer, PA Ian & Julie Ollila coolsspringcountryclub@yahoo.com

For the most up-to-date listings, check our website at www.alpha-1foundation.org.

Comments from the ACT survey (see page 11):
“A+. And Laura is really an awesome person. She took the time EVERY time I called and listened and then explained. Thank you.”