We’re filling research trials — new ones coming!

Letter from the Director

WELCOME to this edition of the Research Registry newsletter. Inside, you will find some interesting reading that lets you know that medicine is always advancing.

I would like to thank the Registry participants who helped to fill many open trials over the past six months. Because of your willingness to participate in research, the National Institutes of Health (NIH) GRADS study of microbes in the lungs finished with a full enrollment. We will be learning about the Alpha-1 microbiome soon. Enrollment in the liver studies is progressing nicely. The inhaled Alpha-1 studies finished enrollment with results to follow. The NIH spousal communication study and Thrive studies also filled quickly. Without your willingness to travel for research, knowledge about Alpha-1 would be immeasurably weaker.

One of the reasons that the use of augmentation therapy remains expensive is that Alpha-1 is a relatively rare orphan disease, and not everyone with Alpha-1 gets emphysema. Therefore, the number of people getting augmentation therapy remains low. What would happen if other diseases were found to benefit from alpha-1 antitrypsin augmentation? Would we have enough drug? Would prices decline? Why would another disease possibly benefit from alpha-1 augmentation?

For many years it has been known that alpha-1 antitrypsin protects the lungs from the effects of a harmful chemical called neutrophil elastase. Neutrophil elastase is one of a family of chemicals called proteases that destroy proteins in our body. Since protease injury happens in many different inflammatory diseases in the body, might alpha-1 infusions help people with these other diseases? Furthermore, alpha-1 antitrypsin has other functions in which it binds to toxic molecules in the body, resulting in improved immunity and reduced inflammation. In this edition of the newsletter, you will hear about one NIH research study that is using alpha-1 antitrypsin to decrease the inflammation associated with islet cell transplantation associated with pancreatitis. Studies like this, to find new uses for an already approved drug, may help to focus the medical community on Alpha-1 and tell our stories in different ways.

At press time there are a few large studies that are close to being launched. So watch your email inbox — and make sure the Registry has your email address! The Registry staff email address is alphaone@musc.edu if you want to add a new email address or make sure that we have your favorite email address listed. As always, we welcome your comments about the work of the Alpha-1 Foundation Research Registry.

Sincerely,

Charlie Strange, MD,
Director, Alpha-1 Foundation Research Registry and ACT Study
Stoller was introduced to Alpha-1 early in his career. He served as co-principal investigator of the groundbreaking National Heart, Lung, and Blood Institute (NHLBI) Registry of Alpha-1 patients in 1989-1996, and the Cleveland Clinic was a coordinating site for the Registry.

In the early 1990s he became involved in the newly founded Alpha-1 Association. He also served on the first expanded Board of Directors for the Alpha-1 Foundation beginning in late 1995.

Meanwhile, his patient experience from the NHLBI Registry involvement grew to form the base of his growing clinical practice. When the NHLBI decided to stop its own Alpha-1 research after its Registry study ended, the Alpha-1 Foundation decided to create an ongoing national group of Clinical Resource Centers for Alpha-1, beginning with the 37 original sites from the NHLBI Registry. The Foundation provided seed funding for Stoller’s growing clinical site to pilot the CRC model. Specifically, the CRC was designed to be a clinical center with Alpha-1 expertise and a multidisciplinary model of care. Today there are 82 CRCs in the United States.

The Cleveland Clinic is a not-for-profit academic medical center with over 3,000 faculty members as well as affiliates in Florida (also a CRC), Nevada, Canada and Abu Dhabi. Cleveland Clinic physicians and associates provide specialty services in numerous departments across all areas of medicine. There are over 100 physicians in the Cleveland Clinic Respiratory Institute, many of whom specialize in COPD care. Alpha-1 patients see Stoller and his COPD colleagues, and the Alpha-1 team involves multidisciplinary specialists including respiratory therapists, pediatric and adult hepatologists (liver doctors), transplant specialists, and a dermatologist for patients who develop panniculitis.

The Cleveland Clinic CRC cares for several hundred Alpha-1 patients from around the nation. Some come for

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You may contact the Alpha-1 Foundation Research Registry staff by email, at alphaone@musc.edu for additional assistance in locating resources related to Alpha-1 research, to obtain information about current research activities, to participate in the Research Network or Registry, or to receive Foundation publications.
consultation with an expert, and then maintain ongoing care closer to home, based on recommendations received at the CRC. Others see Stoller and the Cleveland Clinic for their ongoing Alpha-1 care and needs. The team is able to comprehensively address the complex and variable needs of Alpha-1 patients at any stage of diagnosis and disease progression.

Stoller chairs the Education Institute at the Cleveland Clinic. In addition to his medical knowledge, Stoller has a master’s degree in Organizational Development and an interest in physician leadership development.

He stresses the importance of education for Alphas and their families, and also educates other doctors and healthcare providers regularly. He has hosted many Alpha-1 educational events, most recently the September 2015 Education Day in Cleveland. A Cleveland Clinic liver specialist and respiratory therapist were among the speakers who provided the program for attendees.

Stoller has led the Cleveland Clinic CRC to participate in many Alpha-1 research studies and clinical trials.

In one such study, Stoller implemented a prompt in the Cleveland Clinic electronic medical record to offer physicians “one-click ordering” of Alpha-1 testing for any patient with airflow obstruction. The results of the study were published in the medical journal CHEST in 2009 and demonstrated that testing implementation was improved by this model, but still remained imperfect.

Stoller was an investigator in the NETT trial to evaluate a subset of patients with Alpha-1 for lung volume reduction surgery, and he serves as chairman of the Observational Safety and Monitoring Board for the GRADS study, which is looking at the lung microbiome in patients with either Alpha-1 or another under-recognized lung condition called sarcoidosis.

In addition to being an Alpha Doc, Stoller is a family man who has been married for 33 years. He and his wife have a son, Jake, 26, who played college football at Yale and briefly played for the Pittsburgh Steelers in the National Football League.

Stoller is an avid fly fisherman, distance runner, bicyclist and skier.

He now serves on the Alpha-1 Foundation Board of Directors and its Medical and Scientific Advisory Committee (MASAC). He praises the Alpha-1 Foundation for partnering with many brilliant scientists and community leaders. He is excited about the future of Alpha-1, particularly in the areas of diagnosis and therapeutic opportunities. He sees society’s adaptation to genetic information as a needed step toward newborn screening for Alpha-1 and other disorders.

Stoller emphasizes that continued research is essential to advance new therapies for treating Alphas. In years to come, he hopes that Alpha-1 treatment will provide alternatives to augmentation therapy. He is especially hopeful about the ongoing development of gene therapy and small molecule therapy.

He encourages Alpha-1 testing and diagnosis, even for patients who do not begin augmentation therapy now, because someday there will be additional approaches to disease management. He also stresses the importance of Alpha-1 detection for family members.

To schedule an appointment with Stoller or the Cleveland Clinic CRC, call 216-444-1960.
Q: When should I use oxygen for my Alpha-1 lung disease? Can I use it just in the house? It’s embarrassing to wear those tubes in my nose at the supermarket and restaurants.

A: You should follow your doctor’s advice about using supplemental oxygen. If your oxygen saturation level is low at rest (below 88 percent when checked with a pulse oximeter), then wearing oxygen continuously day and night is more effective than using oxygen only occasionally. If you are using oxygen because your level drops with activity, then it may be reasonable to go without oxygen when you are seated at rest but to use your oxygen during activity, such as when you are out and about.

It is true that people are often embarrassed or dislike wearing oxygen because it is a visible reminder of the deeply personal matter of having COPD. One good way to think about it is that the benefits – potentially lengthening your life and allowing you to be more active – offset the embarrassment. There are also some cosmetically appealing devices to deliver oxygen, like pendant devices, eyeglasses, or direct delivery of oxygen into the windpipe through a thin tube placed in the neck that you can cover with a chain, necklace or scarf. You might discuss these with your doctor if the tubes in your nose are too embarrassing or uncomfortable for you that they discourage you from using the oxygen.

Important studies done in the 1970s showed that, in patients with COPD (chronic obstructive pulmonary disease, not specifically due to Alpha-1), having a blood oxygen saturation level of less than 88 percent carries risk. In those studies, patients with low oxygen levels who used supplemental oxygen lived longer than those who did not. This is why supplemental oxygen is frequently prescribed for Alphas with COPD when oxygen measurements drop below 88 percent.

Much less information is available about the benefits of using oxygen when oxygen levels in the blood at rest are adequate, but the blood oxygen level drops during activity or during sleep. However, supplemental oxygen is often prescribed under these circumstances as well.

To clarify whether oxygen is helpful for people who have COPD and only slightly decreased blood oxygen levels at rest, a multicenter trial sponsored by the National Institutes of Health and by the Center for Medicare and Medicaid Services (CMS) is currently being completed. This trial, called the Long-term Oxygen Treatment Trial (or LOTT), will help clarify whether supplemental oxygen is truly helpful to improve survival or lessen all-cause hospitalization for people with COPD (including Alpha-1) whose oxygen levels at rest are only mildly decreased or whose oxygen levels only drop with activity.

When the results of the LOTT trial are available (hopefully within the next year), we will all be keen to learn how the results of that study influence current thinking.

Q: I’m a ZZ Alpha. I understand that life expectancy is only a little over five years after a lung transplant. Then there are the anti-rejection pills you have to take every day. For those reasons, I plan to just stick with augmentation therapy all my life. Am I wrong? Should I consider a transplant?

A: Considering a lung transplant is a complicated and very personal decision. Of course a lung transplant carries risk, both related to the operation itself and the medications needed after the transplant. That said, for people with severe loss of lung function whose quality of life is poor because of their COPD, a lung transplant can be a very appealing option.

Survival after a lung transplant is measured statistically, but no one can predict how your particular lung transplant would turn out. The rate of survival over time after transplant is measured as a percentage of all the transplant recipients alive at the end of that post-transplant interval. Five-year
survival rates after double lung transplantation for common COPD are approximately 65 percent, and a little higher for Alpha-1, with some variation across different transplant centers. The other way that outcomes after lung transplant are summarized is in the median survival rate: This is the estimated point at which 50 percent of all transplant recipients are still alive.

According to the International Society for Heart and Lung Transplantation, the median survival after lung transplant for common COPD is 5.5 years and for Alpha-1 it is 6.5 years. It is very important to remember that these probabilities do not apply to an individual patient. They are like averages that summarize the experience for a large population, but not for any one person in that population. Some people who have undergone lung transplantation are still doing well more than 20 years after their transplant.

In the end, the decision to pursue a lung transplant requires a deep understanding of the risks and benefits and a commitment to follow a specific protocol after the transplant. Centers that perform lung transplants have doctors, nurses, and therapists who specialize in the care of lung transplant recipients. These experts can provide a well-informed discussion that can help you to sort out this very challenging decision.

**MZ ‘carriers’ needed for COPD study**

Are you an Alpha-1 carrier – is your genotype MZ, or do you have MZ relatives?

Researchers at the Medical University of South Carolina (MUSC) are conducting a study to better understand why some people with the MZ genotype develop chronic obstructive pulmonary disease (COPD) while others do not.

**In order to participate, you must:**

- Have the Alpha-1 genotype MZ
- Have an alpha-1 antitrypsin (AAT) level of less than 16uM or 83 mg/dL
- Be over age 18

Participants will receive an advanced genetic sequencing test to look for changes in the Alpha-1 gene that are not routinely tested, but which might predict COPD risk. There are also surveys to complete about your lung health. Travel is not required.

Please consider participating in this important study! For more information or to get involved, call the study team at 843-792-8438 or email alphaone@musc.edu.
The Alpha-1 Coded Testing (ACT) study now can detect the F and the I mutations, two of the rare Alpha-1 gene mutations. These alleles – variations of a gene – were added to the test in August 2015. This expansion of the testing platform represents advances in both genetic testing and understanding of Alpha-1.

ACT is supported by the Alpha-1 Foundation and has offered free and confidential testing for Alpha-1 since 2001. Over 22,000 people have learned their genotype by testing through ACT.

For the participant, the ACT test involves filling out a consent form and questionnaire, doing an easy finger stick and mailing in a blood sample, and receiving results in your mail a few weeks later. The complex laboratory analysis performed on each blood sample can often be forgotten.

Traditionally the test has “spot-checked” the Alpha-1 gene for the most common mutations, or deficiency alleles, through a method called genotyping – usually designed to detect the S or Z genes in your body. Deficiency alleles are those that reduce the amount of circulating alpha-1 antitrypsin (AAT) in the blood. An AAT level is also measured for ACT participants to make sure that the quantity of AAT in the blood is consistent with the genotype. Two deficiency alleles, the S and the Z, are responsible for most cases of Alpha-1.

Now, the ACT genotyping platform has been expanded to detect the F and I mutations, in addition to the S and the Z. The F allele is thought to be a dysfunctional allele, rather than a deficiency allele. This means that the F allele produces a near-normal amount of AAT, but the protein does not work effectively to protect the lungs. Dysfunctional alleles can be tricky to detect because of the normal quantity (level) of AAT that may be measured in the blood. Therefore, only tests that are specifically designed to look for the F allele are able to detect it.

Alphas with two deficiency alleles (such as ZZ or SZ) have correspondingly low AAT levels. In contrast, people with Alpha-1 involving a dysfunctional allele (such as FF or FZ) have a higher AAT level — yet they are still at risk for Alpha-1 lung disease. How high the risk is for specific genotypes involving the F allele is not yet known. The F is not believed to increase risk for liver disease.

The I allele is associated with a somewhat reduced amount of AAT in the blood. When combined with another abnormal allele (for example, II or IZ), the risk for Alpha-1 lung disease may be increased. The I allele is not known to increase risk for liver disease.

All Alphas should know their genotype, or which two versions of the Alpha-1 gene they inherited. The Alpha-1 genotype determines the quantity and function of the Alpha-1 protein in our bodies, which in turn determines our risk for disease, medical recommendations and also the risk to family members.

As testing becomes more advanced, some people wonder if they should be tested again. The answer to this varies based on the person’s original test and result, family history and symptoms.

If you have questions about Alpha-1 testing or genotypes, we encourage you to call Kim Brown, our genetic counselor, at 1-800-785-3177 to discuss your own unique situation.
The Search for a Cure

Can you find the words below, all found in this Registry Update newsletter?
By Deirdre Walker, Registry Coordinator

(Answers, page 11)

Search for a Cure

N E L R O A M U T A T I O N
E H I D X L T T L A R N L S
E E V N Y L N I W R E N N L
A A E A G E I A O L S R S N
T A R L E L R T A R P T P O
H L S E N E C I O T I R D I
E P A V N O R L R E R A I T
R H I E D T E E E T X A N A C
A A S L R S L I G E T S G E
P S L C N L I O N R I P N T
I R A U O R C O U C O L O E
S A O T E R L O L I N A S D
T C S F A M I L I Y S T N I E
E C T E S T I N G E N T S L

Word List:
ALPHA
THERAPIST
TESTING
OXYGEN
DIAGNOSIS
DETECTION
COUNSELOR
FAMILY
LUNG
DOCTOR
STOLLER
EXERCISE
ALLELE
LIVER
TRANSPLANT
CLEVELAND
MUTATION
AWARENESS
RESPiration
TRIAL
When pancreas is removed, AAT may help prevent diabetes

While much of the work associated with alpha-1 antitrypsin (AAT) has been directed at lung and liver disease, there are many more diseases that need cures. One of these diseases is chronic pancreatitis.

Chronic pancreatitis is ongoing inflammation of the pancreas gland, an organ located in the abdomen that has a duct that connects to the intestine. The pancreas gland is responsible for excreting many of the enzymes that allow us to digest food. These enzymes cause inflammation if they get into the body’s tissues. The pancreas gland also secretes chemicals into the blood. The most important of these is insulin, made by cells called islet cells that reside in the pancreas.

Pancreatitis can be very painful. Inflammation and destruction of the pancreas gland is caused by a variety of conditions including some common drugs, high levels of triglycerides, certain hereditary conditions, or too much alcohol. The duct that leaves the gland can get scarred and blocked and the accumulating pancreas enzymes can further destroy the gland. The result is a painful condition that has few cures. One of the treatments is surgical removal of the pancreas gland to reduce the pain. The problem is that all of the islet cells are also removed, taking away the patient’s insulin. This instantly makes the patient diabetic, with the risk of all that disease’s complications.

A potential treatment is autologous islet cell transplantation (autologous means that cells are taken from a person, then later transplanted back into the same person).

This is a technique in which the pancreas gland is taken to the laboratory after removal, while the cells are still alive. The pancreas is then gently digested to break up the gland into all of the different cell types. The islet cells are separated and injected back into the patient. The injection site with the most success is into a large vein called the portal vein that goes to the liver. In this procedure, injection of islet cells into the portal vein allows the islet cells to travel to the liver and establish themselves as insulin-producing cells.

In the best outcome, the patient would not be diabetic at all. The number of cells that survive determines how diabetic a patient will be after removal of the pancreas. This surgery is done at only a small number of specialty centers, because of the detail and expertise involved.

Hongjun Wang, PhD, Katherine Morgan, MD, David Adams, MD, and their team at the Medical University of South Carolina have been experimenting in mice to find out how to get the most functional islet cells after transplantation. They found that infusion of alpha-1 antitrypsin improved implantation of the islet cells in the liver and prevented the mice from becoming diabetic.

The team recently received a grant from the National Institutes of Health (NIH) to infuse AAT into pancreatectomy patients for a month by weekly IV infusions — exactly the way that Alpha-1 patients currently get their infusions. Whether humans will act like mice remains to be determined, but the goal is to lessen the number of patients who are diabetic at the end of a year.

The anti-inflammatory properties of AAT are still not completely known. Studies such as this one help us to learn how AAT works in the body to lessen cellular stress. The study team is also open to collaborations with other researchers, using the biobank that will be generated by this study.

The research team welcomes contact or referral of patients to Katherine Morgan, MD (morganka@musc.edu) or Hongjun Wang, PhD (wangho@musc.edu).
Genetic Counseling call volume grows

By Kimberly Brown
Director, Alpha-1 Foundation Genetic Counseling Program

On Sept. 23, 2015, the 4,000th caller reached the Alpha-1 Foundation Genetic Counseling Program (GCP) to discuss what her Alpha-1 test results mean for her future and her family.

The GCP offers free and confidential telephone-based genetic counseling and assistance to Alphas, family members and healthcare providers. The Alpha-1 Foundation supports the GCP, which began in 2007.

The identity of all callers is strictly confidential. Each call is recorded in a secure and confidential database in order to assess program volume and activity. A call record also improves the quality of service for people who call more than once as they think of additional questions. Over the last year (2014-15), the program helped an average of 62 callers per month. This is more than double the call volume from the early days of the GCP. The first year, we had an average of 24 calls per month. The top reasons for calling include whether and how to be tested for Alpha-1, what test results mean, and discussion of next steps after diagnosis.

The increased number of calls over the years correlates with improvements in Alpha-1 awareness and availability of testing. The topics frequently discussed are also growing to include conversations about more rare Alpha-1 alleles, which is consistent with advances in Alpha-1 laboratory detection methods.

Many Alphas wonder what their test results mean for them, what they can do to stay healthier, and what the next medical steps are after being diagnosed. Conversations with callers are always personalized, based on individual test results, health status and the caller’s needs.

Because Alpha-1 is a family matter, genetic counseling often involves a discussion of who else may benefit from testing. Mental health is also important and the genetic counselor frequently discusses coping strategies, support group involvement and community resources that can help an Alpha adjust to living with Alpha-1.

About 30 percent of our current callers are healthcare providers with an interest in Alpha-1 testing and how to best help the patients who receive abnormal results. We applaud them for testing and for their interest in Alpha-1.

It’s a busy and exciting time for the GCP! We are thrilled that so many are using this service – yet we know there are many undiagnosed Alphas and family members still out there. We look forward to connecting with many more Alphas in the future.

We encourage you or your relatives to call toll-free at 1-800-785-3177 with questions about any aspect of Alpha-1, testing, genetics, or resources. You can also check out our genetic counseling FAQs at tiny.cc/gc-faqs.

WHAT IS GENETIC COUNSELING?
Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates:

• Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence.
• Education about inheritance, testing, management, prevention, resources and research.
• Counseling to promote informed choices and adapting to the risk or condition.

For more information, see the National Society of Genetic Counselors website: nsgc.org.

Kimberly Brown at the Medical University of South Carolina (MUSC) directs the Alpha-1 Foundation Genetic Counseling Program. She received her Master of Science in Medical Genetics degree from the University of Cincinnati in 2009 and is a board-certified genetic counselor (CGC). She has worked with the Alpha-1 Foundation since June 2014.
Don’t give up on exercise!

If you don’t exercise now, begin gently, do it regularly, and build over time

By Alysha Carlos
MUSC research assistant

For Alphas with lung disease, exercise may seem impossible. Especially at the beginning, it can be difficult, perhaps even painful.

Some people with lung disease get short of breath simply trying to carry out activities of daily living – bathing, getting dressed, walking around a supermarket – so asking these people to exercise may seem a bit cruel. But exercise has great benefits for people with lung disease.

Simple exercises such as walking around the block can help improve shortness of breath. If you have severe lung disease that makes a walk around the block seem too difficult, even small activities like making short trips to the mailbox can help.

You should check with your doctor before beginning an exercise program. The ideal exercise plan, if it is available to you, is a pulmonary rehabilitation program, where you will be monitored by experts on exercise for people with lung disease.

When you begin more physical activity than you are used to, it is likely to be hard. You may find yourself quickly becoming short of breath. It’s very important that you don’t push yourself too hard, because this could lead to injury. More likely, over-exercising at first may leave you with sore muscles that discourage you from continuing; that makes it difficult to develop the habit of exercising regularly. But it is also important to push yourself, and your muscles, to work a little harder than they are used to. By doing this, you will train your body to become stronger over time.

Think of your lungs the way you would think of a body builder’s biceps. What do body builders do to increase their muscle mass and to make themselves stronger? They work out regularly. By working those muscles every day, they get stronger over time.

While your lungs are organs and not muscles, your diaphragm is a muscle. The diaphragm is a sheet-like muscle that rests beneath your lungs. It’s essential for inspiration and expiration, also known as breathing in and out. When you exercise, you breathe more deeply – and you are strengthening this muscle and therefore improving your breathing efficiency.

Exercise also helps your lungs directly. Located inside your lungs are tiny balloon-like structures called alveoli. The function of your alveoli is to exchange gases, which in this case is the exchange of oxygen and carbon dioxide. When you exercise, you need to breathe in more oxygen and breathe out more carbon dioxide. During exercise your breathing rate increases because the muscles are delivering more carbon dioxide to the bloodstream that must be eliminated through the alveoli.

Regular exercise, causing the muscles to work harder, also makes them more efficient. And making muscles more efficient results in less carbon dioxide production. By gradually developing a stronger set of muscles, the lung disease patient can go farther with less shortness of breath because they are not producing as much carbon dioxide.

So remember this when you are exercising and trying to find the motivation to keep going: you can do it, your lungs will thank you for it, and your improved fitness will make life more enjoyable.
Search for a Cure

NELRO AMUTATION
EHIDXLTTLARNLSS
EENVYNLNIWRENNL
AAEAGEIAOLSRSN
TARLELRTPOTPO
HLSENECEITORIDIR
EPAVNORLERESENTIT
RHIETTEETXANAC
AASLSLIGETSGEG
PSLCNLONRIPNT
IRAUCOLOE
SOATERLOLINASD
TCSFAMILYSNIE
ECTESTINGENTSLS
Calendar 2016

### Building Friends for a Cure Events

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<thead>
<tr>
<th>Date</th>
<th>Event Name</th>
<th>City, State</th>
<th>Contact &amp; Email</th>
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<tbody>
<tr>
<td>Mar. 12</td>
<td>Celtic Connection</td>
<td>Newton, MA</td>
<td>Bob Healy <a href="mailto:Bobhealy125@msn.com">Bobhealy125@msn.com</a></td>
</tr>
<tr>
<td>Apr. 4</td>
<td>Friends for a Cure Golf Event</td>
<td>Jacksonville, FL</td>
<td>Sarah Johnson <a href="mailto:sarah_shirk@comcast.net">sarah_shirk@comcast.net</a></td>
</tr>
<tr>
<td>Apr. 23</td>
<td>Hero Walk</td>
<td>Henrico, VA</td>
<td>Pam Vanscoy <a href="mailto:Vaalpha1herowalk@yahoo.com">Vaalpha1herowalk@yahoo.com</a></td>
</tr>
<tr>
<td>Jun. 18</td>
<td>George Washington Bridge Walk</td>
<td>NY/NJ</td>
<td>Joe Reidy <a href="mailto:joereidy@verizon.net">joereidy@verizon.net</a></td>
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For more information about Building Friends for a Cure, contact Angela McBride, (877) 228-7321, ext. 233.

### Education Days

<table>
<thead>
<tr>
<th>Date</th>
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<tbody>
<tr>
<td>Feb. 20</td>
<td>Phoenix, AZ</td>
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<td>Mar. 19</td>
<td>New Orleans, LA</td>
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<td>Apr. 30</td>
<td>Louisville, KY</td>
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<td>Aug. 6</td>
<td>Denver, CO</td>
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<td>Sept. 10</td>
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<td>Oct. 29</td>
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For more information about Education Days, contact Kim Caraballo, (877) 228-7321, ext. 323.

### Virtual Support Group Calls

<table>
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<th>Date</th>
<th>Speaker</th>
<th>Topic</th>
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<tr>
<td>Jan. 26</td>
<td>Timely Topics</td>
<td>Alpha-1 State of the Union Address - John Walsh</td>
</tr>
<tr>
<td>Feb. 16</td>
<td>Alpha-1 Kids</td>
<td>Pediatric Lung Issues - Charlie Strange, MD</td>
</tr>
</tbody>
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**To participate:** At 9 pm Eastern, dial: 1-800-920-7487. When prompted, enter the code: **9335 9985**#

For more information about events, contact us, 1-800-228-7321.

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### Alpha-1 Foundation

The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency and to improving the lives of people affected by Alpha-1 worldwide. The Foundation has invested more than $54 million to support Alpha-1 Antitrypsin Deficiency research at 100 institutions in North America, Europe, the Middle East and Australia.

### AlphaNet

AlphaNet, Inc. is a not-for profit organization that provides a comprehensive disease management and prevention program to improve the lives of people with Alpha-1 Antitrypsin Deficiency. AlphaNet also oversees and sponsors clinical trials involving Alpha-1 therapies.

The Registry Update is funded by unrestricted educational grants from:

**AlphaNet, CSL Behring, Grifols**