A new website now, new CRC Registry coming

Welcome to this edition of the Alpha-1 Foundation Research Registry Newsletter. This has been a busy year for the Registry: Many researchers have come to the Registry for assistance in filling their studies. We sent 18 invitations to Registry participants during 2014, and the rapid pace is continuing this year.

If you wonder why you might not have received 18 invitations, we target people who can help to fill an individual study in the quickest way. If it is a small or regional study, we will go first to our Registry participants who have allowed their email to be used. Although we have accurate contact information for 93% of Registry enrollees, we have email addresses for only half. If you would like to be invited to more studies, please send your email or other updated contact information to alphaone@musc.edu.

The second way that we have been busy is in building the new Alpha-1 Foundation Clinical Resource Center (CRC) Registry. We’ve long known that the ability to learn more about Alpha-1 is dependent on having detailed longitudinal data. When researchers see a patient on one day, they see a snapshot of their health or disease at that moment. This “cross sectional” data is useful, but not as useful for slowly progressive chronic diseases like Alpha-1. Instead, data that is collected over many years is much more important – to establish cause and effect relationships and to determine the individual course of disease. Most of you already know this, and keep detailed health records on lung and liver function test results, on medications you take, and on other health conditions.

But Alpha-1 researchers often need more: They often need blood samples, detailed genetic test results, and standardized questionnaires. Therefore, the goal of the CRC Registry is to have Alphas visit one of the more than 80 Clinical Resource Centers around the United States, and to enroll in the CRC Registry at the time of their visit. This rollout will take years, and every CRC may not have the resources to participate at the beginning. But over an extended period, your repeated visits, blood samples, and questionnaires will create a rich data source to help us find a cure for Alpha-1.

Exciting news: Our new Alpha-1 Research Registry website is now public. Be sure to check out the new site by visiting http://alphaoneregistry.org. One reason we built the new website is to serve as a portal for researchers to access the new CRC Registry. A big reason you should be excited is that we have added a page telling you about all the current study invitations being managed by the Registry!

Continued on page 2
Continued from page 1

Instead of trying to find where you put an invitation letter, you can go to our new website and find the contact information you need. Please explore our new website. We welcome your feedback.

Some of our studies this year have not filled as quickly as we had hoped. Have you always thought that you might participate in research one day? If so, and if you have not considered these studies, please reconsider these invitations.

We don’t want to blur the lines between good clinical care for Alpha-1 and the risks and benefits of any given research project. So please read the study invitations carefully and get the details of the study by contacting the study sites. Thank you all for your participation in the Alpha-1 Foundation Research Registry.

Sincerely,

Charlie Strange, MD,
Director, Alpha-1 Foundation Research Registry and ACT Study

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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.
Encouraging Alphas to use their oxygen

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

For anyone who is prescribed supplemental oxygen, many things can get in the way of using it.

For example, sometimes the equipment is heavy to lug around, though that problem has been reduced in recent years with lighter concentrators on wheels. Some people believe that others treat them differently if they are wearing oxygen tubing. Also, many people don’t notice an immediate benefit from using their oxygen.

But supplemental oxygen has many medical benefits, including helping people to live longer. So the Alpha-1 Foundation has funded a study designed to help Alphas use their supplemental oxygen.

First we collected data from a questionnaire mailed to members of the Research Registry. Thank you, everyone who returned this questionnaire! Your answers suggest that people who believe in the medical benefits of oxygen are more likely to use it. For example, people who use their oxygen are more likely to believe that oxygen will help them live longer and will protect their heart. Negative beliefs also influence oxygen use – especially being embarrassed about using oxygen in public, and thinking that oxygen is uncomfortable to use.

Now, I am trying to learn how to motivate people to use their supplemental oxygen. Many people may be aware of the benefits of oxygen, but still have a hard time using it on a daily basis. I have developed a brief phone-based program designed to encourage people to use their oxygen. I am testing this program with a small number of Alphas, so I can get feedback on how to improve it. If you are prescribed oxygen 24 hours per day, and actually use your oxygen less than 15 hours per day, you may be eligible to participate.

To learn more, please contact me at holmk@njhealth.org or 303-398-1509.
Our ACT questionnaires:

By Laura Schwarz
ACT Coordinator

“Do I HAVE to fill out that questionnaire? Can’t I just get the test kit?”

If I only had a dollar for every time I’ve heard those questions!
The answer – you guessed it – is that we HAVE to get those questionnaires filled out – THEN we can send you the test kit!

I want to show you how much we appreciate your time and trouble in filling out our questionnaires. Let me explain why the questionnaires are such essential tools in our research.

The ACT Study, as many of you know, is the free and confidential finger stick test that has been ongoing since 2001. As of March 4, 2015, ACT has 24,020 participants. This is the total number of consented participants.

Of those, we are able to use 18,262 in our research studies – because they have consented after June 2006 when we revised our informed consent form to invite participants to consent for life. We’ve had six different ACT questionnaires, including our current one, that have asked different questions of interest to researchers in the Alpha-1 community (see the chart).

The initial ACT questionnaire, distributed in 2001 through 2002, was mailed in a package containing an informed consent, a blood card with lancets, an instruction sheet and a postage paid return envelope. This questionnaire focused on the risks, benefits, and the psychological impact of home genetic family testing.

To discuss the outcome of this pilot study, a paper called “Genetic Testing for Alpha-1 Antitrypsin Deficiency” was published in the journal *Genetics in Medicine* in 2004. The results showed the interest participants had in establishing an Alpha-1 diagnosis, a high likelihood they would quit smoking if diagnosed with the deficiency, and a desire to share their diagnosis with family members and to encourage them to test.

See “ACT 1” in the chart, showing the number of people who responded and the focus points of the first questionnaire.

ACT Questionnaire #2 investigated the barriers to genetic testing – specifically, why some people return their blood sample and others do not.

The result: We found out that a major reason participants did not return their tests, was the fear of sticking their finger. We wish we had a quick fix for that! (Remember that patients with diabetes do this several times every day to check blood sugar.) Other psychosocial concerns, such as stress induced by genetic testing, showed a difference between those who returned their kits and those who did not return.

From mid-2004 to mid-2006, ACT Questionnaire #3 was distributed. This questionnaire focused on behavioral health issues and further studied the successes of smoking cessation associated with Alpha-1 testing.

The ACT Team celebrated Questionnaire #4, with the transition to new Scantron forms. The reason for the excitement was that our days of manually inputting responses from all the returned questionnaires were over. We sent out the kits with little golf pencils enclosed, so everyone could color in their answers. It worked beautifully! This questionnaire showed the importance of the Internet as a source of information for Alphas.

In September 2010 the ACT Study established an online version – and continued a paper version, so that those who did not have access to the Internet could still request the hard copy forms. Since then we have collected information on correlations between genes and other diseases, such as cancers, heart diseases, sleep apnea, and neurological diseases.

When we introduced our online forms, many more people began testing. As more people got tested, researchers began contacting us more regularly to use our confidential database as a resource. The database for the ACT study now contains about 5,000 MZ carriers, making it a good resource to study why some carriers have risks for lung and liver disease, and some seem completely normal.

I hope this answers the question we started with: We make the ACT questionnaire a participant requirement because we need to build the infrastructure to find a cure for Alpha-1. We ask for the ability to re-contact participants, so we can invite them to consider research studies specific to their genotypes and clinical condition.

Thank you for helping us move forward by taking time and care to complete our surveys!
‘Precision Medicine’

Alphas provide a model of a community that

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

It has been more than 50 years since the discovery of Alpha-1 Antitrypsin Deficiency, 39 years since the Z and S alleles were molecularly defined, and 28 years since the U.S. Food and Drug Administration (FDA) approved augmentation therapy for the treatment of Alpha-1 lung disease.

Many other milestones have been reached in Alpha-1 detection and care due to advances in genetics, medicine, research and awareness. The Alpha-1 Research Registry has been a cornerstone of these advances for more than 17 years, and the ACT study is now in its 14th year of providing free and confidential Alpha-1 testing. Over 20,000 people have been tested in the ACT study, and genetic testing is at an all-time high!

In the larger scientific community, it has been 12 years since the completion of the human genome project and seven years since the Genetic Information Nondiscrimination Act (GINA) was passed, ensuring employment and health insurance protections for those undergoing genetic testing. “Personalized medicine” — medical treatment tailored to the individual patient — is being embraced at accelerated rates in all areas of healthcare.

Now, in 2015, a National Precision Medicine Initiative is under way.

President Obama announced in his 2015 State of the Union Address, “Tonight, I’m launching a new Precision Medicine Initiative to bring us closer to curing diseases like cancer and diabetes — and to give all of us access to the personalized information we need to keep ourselves and our families healthier.”

The National Institutes of Health describes precision medicine as “an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.” The initiative aims to help people understand their own disease susceptibility and help them to receive the right treatments.

The Precision Medicine Initiative advocates genomic typing and facilitating research, two important practices long standard in the Alpha-1 community. Alphas know first-hand how genes influence disease risk and how personalized test results can affect our families and treatments. Alphas recognize the importance of taking part in research to advance disease knowledge and therapies. The Alpha-1 community is an excellent example of how precision medicine practices can improve awareness of risk and disease outcomes.
Developing more and better treatments for cancer is an important near-term objective of the Precision Medicine Initiative. Cancer is a common life-threatening disease that involves both genes and the environment. For many diseases, treatments are still aimed at the general diagnosis and designed for the average patient. A person’s unique differences and molecular signatures of disease, when understood, help people get the personalized treatment that they are likely to respond to best.

Alpha-1 COPD is a prime example: only a blood test can determine who developed COPD due to Alpha-1 rather than other common causes, so everyone with COPD should be tested. The Alpha-1 COPD group often benefits from augmentation therapy, which is not indicated for people with non-Alpha-1 COPD. Without the Alpha-1 test, standard COPD treatments may be helpful, but do not target the underlying reason for Alpha-1 lung diseases. Precision medicine can help other disease communities to use genetic and biologic testing to make advances in detection and treatment.

Creating a voluntary national research cohort is an important long-term goal of the Precision Medicine Initiative. This is important because the ability to meaningfully interpret personalized test results stems largely from research. Access to large amounts of genomic and clinical data helps researchers find specific risk factors such as genetic markers and evaluate treatment and outcome data. Doctors with this information can make personalized recommendations for each individual with greater evidence and confidence. This “me-for-you and you-for-me” approach is based on people choosing to share genomic and health data with qualified researchers, also knowing personal benefit may come from general improved knowledge. The Precision Medicine Initiative will seek at least a million American volunteers for this purpose.

Alphas exemplify the impact of a community committed to research. Every Registry member has helped the Alpha community at-large by sharing genotypes and clinical information with medical researchers and participating in Alpha-1 studies. As a result, today’s Alphas receive better information and care than ever before. Our continued commitment to research promises further Alpha-1 understanding, therapeutic advances, and one day—a cure!

Alphas have come a long way, but there’s still a long way to go. Alphas share a common ground and common cause; yet every Alpha is unique, with a one-of-a-kind biologic profile, lifestyle and family story.

So we stand to benefit—individually and communally—from research toward an Alpha-1 cure and personalized healthcare. Your continued commitment to research is still essential and, as always, the Alpha-1 genetic counselor is available at 1-800-785-3177 to help you understand how your Alpha-1 genetics affect you and your family members.
More adults with Alpha-1 are needed to enroll in a study that will provide vital information about which Alphas are likely to develop liver disease and how fast the disease progresses. Both Alphas with liver disease and those with no liver disease symptoms are eligible for the study, funded by the Alpha-1 Foundation.

The study is intended to identify the genetic and environmental factors that are important in the development of Alpha-1 liver disease. Liver disease in adults often has no symptoms and can remain undiagnosed for years. This will be the first study that examines a group of adult Alphas over five years to understand the progression of Alpha-1 liver disease. Any family members of study volunteers who themselves have PiZZ Alpha-1 are also encouraged to enroll, so the study can compare possible liver injury among members of the same family.

Alphas enrolled in the study will complete annual research visits for five years. To be in the study, you must be at least 18 years old and have a documented diagnosis of PiZZ. Participation requires a visit to a study center upon enrollment, as well as a visit each year for the next four years. A liver biopsy is performed at enrollment and another biopsy at the end of the 5-year study.

One fan of the adult liver study is Janet Fonner of Indiana.

“Believe me, if I can do it, practically anyone can. How many people get to participate in their own cure?” says Fonner, a healthy Alpha who is taking part in the liver study.

Fonner’s late brother, Kevin Salinetro, had Alpha-1-related emphysema.

There is no cost to take part in the study, and funds are available to cover travel expenses; contact the study coordinator nearest you for details. Besides an in-depth examination from an Alpha-1 liver specialist, participants will receive copies of their test results and liver biopsy reports to share with their own physician.

Alphas can enroll at one of three U.S. sites, one on each coast and one at a central site in St. Louis, MO.

If you’d like to volunteer, or want more information, contact the study coordinator at the site closest to you: For Saint Louis University, contact Jackie Cerkoski, RN, BSN, at 314-977-5239, or email cerkoski@slu.edu. For the University of California San Diego, contact Phirum Nguyen at 619-471-0774 or psnguyen@ucsd.edu. For Boston University School of Medicine, contact Rosemary Nagy, 314-977-9350, or magy@slu.edu.

More information is available at www.clinicaltrials.gov. Search for study number NCT02014415.
Our research group is seeking ZZ Alphas with liver disease to participate in a controlled clinical trial to determine the safety and efficacy of the drug Tegretol, or carbamazepine. The trial is based on laboratory findings that carbamazepine reverses liver damage and scarring in a mouse model of Alpha-1. Our work suggests that carbamazepine is one of a newly discovered class of drugs that appear to work by stimulating natural processes that destroy the “bad” alpha-1 antitrypsin protein stuck in the liver.

Carbamazepine has been used safely for many years in the treatment of epilepsy, chronic pain and depression. So far we have enrolled 14 participants; an additional 16 are needed.

Liver biopsy and liver pressure determinations are done at the beginning and the end of the trial. These are carried out together as one procedure in which a special catheter is introduced into a vein, usually through the neck. The catheter is threaded to the liver using an x-ray machine for guidance. Participants are given sedation for the procedure. The outcome of the trial will also be determined by history of symptoms, changes found by physical examination and blood tests that are done at intervals during and after the 12-month treatment period.

The drug will be given at the same dose that is used for epilepsy or mood stabilization. It will be started at a lower dose and slowly increased over four weeks to reduce the likelihood of any allergic reaction. The study is taking place at the University of Pittsburgh Medical Center, with five follow-up visits after the original two screening visits to Pittsburgh. Funds are available to cover travel expenses.

To be eligible, you must have Alpha-1 Antitrypsin Deficiency (ZZ) with signs of elevated liver pressure, among other criteria. We will need to contact your doctor to find out if you meet the trial criteria.

Contact Adam Kufen at adam.kufen@chp.edu or at (412) 692-6558 for more information.

Old drug, new Alpha-1 liver treatment?

By David H. Perlmutter, MD
Professor and Chairman of Pediatrics, University of Pittsburgh

In 2012, our team of researchers at Penn State, in collaboration with the Alpha-1 Research Registry, surveyed how married adults communicate about Alpha-1 and how these communications shape Alpha-1 experiences and quality of life for both partners. The Alpha-1 Foundation funded that pilot study.

Our research team recently received funding from the National Human Genome Research Institute (NHGRI) to extend our research. We launched a new survey this spring to additional married couples, as well as unmarried adults, to gain greater insight into communication patterns and Alpha-1 experience.

The 50 couples that took part in our 2012 pilot project provided new insights into living with Alpha-1. Having both spouses participate brought unique information on how Research Registry members and their spouses cope with Alpha-1. Findings of this initial work appeared in academic journals such as the Journal of Genetic Counseling and Health Communication.

The 2015 study surveyed more than twice as many couples to expand on this important work. We also surveyed unmarried adults in the Research Registry in order to learn about their Alpha-1 communication experiences. The goal of this project is to improve understanding of communication issues related to Registry members, and ultimately to empower the Alpha-1 community to cope better with health challenges.

Survey invitations were sent this spring and we thank those who responded! We look forward to sharing our research findings in future newsletters and at Alpha-1 events.

Rachel Smith, PhD, is Associate Professor of Communication Arts and Sciences & Human Development and Family Studies.

How Alpha couples, singles communicate

By Rachel Smith, PhD
Penn State University
There’s still time to be a partner in research!

The Alpha-1 Foundation is committed to finding a cure for Alpha-1 and to improving the lives of people affected by Alpha-1 worldwide. Being a volunteer for research makes you a partner in these missions. You may have seen invitations for the two studies below before, but we want you to know it’s not too late to sign up!

**Genomic Research in Alpha-1 Antitrypsin Deficiency and Sarcoidosis (GRADS) is looking for more MZ and ZZ participants!**

An important study by the National Institutes of Health (NIH) is scheduled to end on June 20, 2015 – and still needs about 20 more participants. This study enrolls both MZ carriers and ZZ participants, either on or off augmentation therapy. This exciting study is looking at the lung microbiome, or the microscopic “bugs in your lungs,” and how those bacteria, combined with Alpha-1, affect each other. If you or a family member are MZ or ZZ, between 35-80 years old, and are interested in becoming part of this research effort, please contact a study coordinator below. There are eight sites currently enrolling for this study and the Alpha-1 Foundation will provide travel reimbursement to help you reach one of the GRADS centers. The study consists of two visits, and includes questionnaires, a blood draw, PFTs (breathing tests), a 6-minute walk test, a CT scan and a bronchoscopy. You can learn more by visiting [www.gradslung.org](http://www.gradslung.org). Or call:

**University of California – San Francisco, San Francisco, CA**  
Contact: Joris Ramstein (415-502-2378)

**University of Pittsburgh, Pittsburgh, PA**  
Contact: Stephen Bruno (412-605-1550)

**National Jewish Health, Denver, CO**  
Contact: Briana Barkes (303-398-1699)

**Johns Hopkins University, Baltimore, MD**  
Contact: Linda Breslin (410-550-0551)

**University of Arizona, Tucson, AZ**  
Contact: Nancy Casanova (520-626-4110)

**University of Pennsylvania, Philadelphia, PA**  
Contact: Ayannah Fitzgerald (215-662-6041)

**Medical University of South Carolina, Charleston, SC**  
Contact: Deirdre Walker (843-792-1219)

**Yale University, New Haven, CT**  
Contact: Donna Carrano (203-737-5061)

**Severely Deficient Alphas needed for study of inhaled augmentation therapy**

Kamada High Quality Pharmaceuticals is sponsoring a study of an inhaled form of augmentation therapy. The current treatment for people diagnosed with Alpha-1 related lung disease is augmentation therapy: This involves infusions, usually weekly, of the alpha-1 antitrypsin protein, and until other therapies become available, it is considered ongoing for life. This is a double-blind study of the daily use of Kamada- API for inhalation. Double-blind means that Alphas with lung disease will be randomized to receive the study medication at one of two doses (80mg/day or 120 mg/day) or a placebo (a substance containing no study drug). Inhalation of the drug will be done at least once a day, but up to two times a day. There are two medical centers currently enrolling. Please contact the study coordinators for more information.

**University of Texas Health Science Tyler:** Contact - Jan Hoeft at janice.hoeft@uthct.edu or 903-877-5518

**University of Florida:** Contact- Joanna Nolte at joanna.nolte@medicine.ufl.edu or 866-229-6312
Since the human genome was mapped in 2003, scientists have developed many ways to identify genes and their functions, and to learn and alter the role they play in disease.

During the past 5 years, interest in biorepositories (often referred to as simply biobanks) has grown tremendously and fueled several important national and international initiatives. In 2009, Time magazine called biobanks one of the “top 10 ideas that are changing the world.”

Biobanks are libraries for storing biological specimens for clinical or research purposes. Human biological materials such as tissue, blood, plasma, and urine can be used for diagnosis and basic research. The specimens are frequently labeled with demographic information like age, race, and gender, as well as clinical data, such as the disease diagnosis of the patient who donated the bio specimen.

When patients participate in research, or undergo procedures such as a blood draw, biopsy or surgery in which a specimen is removed, it is often possible for a small amount of the specimen to be stored and used later for further research. Many patients have given consent for their bio specimens to be used, in the hope that the resulting knowledge might help other patients in future years.

It is common for these specimens to be used to find and test ways to deliver drugs or agents to specific cells. They can help to identify how diseases progress and vary; help to find which patients are more likely to respond to specific drugs; determine which treatment is appropriate; or develop screening tests to find biomarkers that are associated with certain stages or types of disease.

Biobanks are critical to modern “personalized medicine” research that can improve clinical outcomes for patients.

More and more patients now understand the importance of biobanks in advancing research and possible cures for their own disease. Researchers depend on a ready supply of high-quality biological specimens – human tissue, blood, cells and fluids – with the associated clinical data.
# 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>Aug. 9</td>
<td>Step Forward for Alpha-1 Colorado</td>
<td>Denver, CO</td>
<td>Angela McBride <a href="mailto:amcbride@alpha1.org">amcbride@alpha1.org</a></td>
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<tr>
<td>Sept. 19</td>
<td>Get the Scoop on Alpha-1</td>
<td>Cedar Rapids, IA</td>
<td>Frank and Terri Loutsch <a href="mailto:loutschfrank@monnmail.com">loutschfrank@monnmail.com</a></td>
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<tr>
<td>Sept. 25-27</td>
<td>Escape To The Cape</td>
<td>Cape Cod, MA</td>
<td>Angela McBride <a href="mailto:amcbride@alpha1.org">amcbride@alpha1.org</a></td>
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<td>Oct. 4</td>
<td>Step Forward For Alpha-1 Walk</td>
<td>Mishawaka, IN</td>
<td>Terry and Tom Corron, Tom Corron <a href="mailto:tcorron@live.com">tcorron@live.com</a></td>
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<td>Oct. 10</td>
<td>50’s Friends For A Cure Dance</td>
<td>Shoemakersville, PA</td>
<td>Larry &amp; Marian Hoffman <a href="mailto:alfalfaalphagroup@gmail.com">alfalfaalphagroup@gmail.com</a></td>
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<tr>
<td>Nov. 7</td>
<td>Step Forward For Alpha-1 Walk</td>
<td>Orlando</td>
<td>Angela McBride <a href="mailto:amcbride@alpha1.org">amcbride@alpha1.org</a></td>
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# Education Days

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<tr>
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<tr>
<td>Sept. 19</td>
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## Alpha-1 National Education Conference

- **July 24-26** Garden Grove, CA

## Support Group Meetings

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<th>Group Name</th>
<th>City, State</th>
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<tr>
<td>June 15</td>
<td>Idaho Alpha-1 Outreach</td>
<td>Meridian, ID</td>
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<td>June 20</td>
<td>Dakotaland Alphas</td>
<td>Sioux Falls, SD</td>
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<td>AlphaBurgherZ</td>
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<td>Bayou City Alphas</td>
<td>Houston, TX</td>
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<td>Central Nebraska Alphas</td>
<td>Grand Island, NE</td>
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<td>June 24</td>
<td>NY/NJ Alphas</td>
<td>New York City, NY</td>
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<td>June 27</td>
<td>Hoosier Alphas</td>
<td>Indianapolis, IN</td>
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<td>Alpha Opportunities</td>
<td>Westchester, PA</td>
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<tr>
<td>July 9</td>
<td>Alpha Pack Northern Lights</td>
<td>Milwaukee, WI</td>
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<td>August 8</td>
<td>Dakotaland Alphas</td>
<td>Sioux Falls, SD</td>
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<td>August 15</td>
<td>Bayou City Alphas</td>
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<td>Central Virginia Alphas</td>
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<td>Alpha Gators</td>
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<tr>
<td>August 24</td>
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<td>Sept. 12</td>
<td>Connecticut Nutmeggers</td>
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## Virtual Support Group Calls

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<tr>
<td>June 16</td>
<td>Cathey Horsak</td>
<td>Alpha-1 Kids National Conference Activities Q&amp;A</td>
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<tr>
<td>June 23</td>
<td>Marty Zamora, MD</td>
<td>Pre and Post Transplant Considerations</td>
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<td>June 30</td>
<td>Skip Scribner, Pres</td>
<td>Traveling with Oxygen</td>
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<tr>
<td>August 4</td>
<td>Teresa Kitchen, RN</td>
<td>Caregiving for Alphas</td>
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<tr>
<td>August 18</td>
<td>Experienced Parents</td>
<td>Newly Diagnosed Q&amp;A</td>
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**Directions for Dialing in:** On the assigned day at 9 pm Eastern, dial this number: 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.

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The Registry Update is funded by unrestricted educational grants from: **AlphaNet, CSL Behring, Grifols**