Make sure you get research invitations!

Letter from the Director

WELCOME to this winter’s version of the Alpha-1 Foundation Research Registry Newsletter. The Registry has been busy over the past six months and has fulfilled a record number of requests from researchers to recruit for their studies. Some of these requests are very regional, some come only if we have an accurate email address for you, and others are more general. However, if you have not received research study advisories over the past six months, then something is amiss. Please call the Registry toll-free at (877) 886-2383 to assure we have correct contact information for you.

We welcome Deirdre Walker as the new Registry Coordinator. She graduated from North Carolina State University in 2008 with a degree in Genetics and has worked in stem cell research at the Medical University of South Carolina for the past two years. Prior to working at MUSC, she worked in a cell biology lab at GenPhar, Inc. for two years. She brings important genetics experience to the MUSC team as we continue to enhance the capabilities of the Registry. She left stem cell biology because the stem cells couldn’t carry a conversation very well – she wanted a job that had more human interaction. Please introduce yourselves at education days and welcome her into the community.

This edition of the newsletter highlights some research studies that still need participants. Although the decision to participate in research is always yours, advances in Alpha-1 would never be made without the continuing commitment of this wonderful community to support meaningful advances in Alpha-1 research.

Also we invite you to visit the new website of the Alpha-1 Foundation Clinical Resource Centers (CRCs) at http://alpha-1foundation.org/clinical-resource-centers/ As the CRC numbers continue to grow, we are pleased to highlight them in each edition of the Registry Newsletter. If you are not now getting study invitations by email and would like to receive email contacts, please contact the Registry with an email – at alpha-one@musc.edu -- and we will add your email address to your contact information. We hope you enjoy this edition of the Alpha-1 Registry Newsletter.

Sincerely,

Charlie Strange, MD,
Director, Alpha-1 Foundation Research Registry
Professor of Pulmonary and Critical Care Medicine
Medical University of South Carolina
As a teen in Sweden, this Alpha helped with research of Alpha-1 co-discoverer.
And 35 years later, she still competes in triathlon events.

Dr. Strange received a letter last spring from a woman in Kentucky named Gunilla Bowling.

Bowling was born in Malmo, Sweden. In 1976, when she was 17, she worked a summer job at Malmo General Hospital, where she sterilized dishes from the lab.

Soon after her job began, she heard that the professors needed volunteers to donate blood for a study using electrophoresis (a procedure which enables the sorting of molecules, such as DNA or proteins, based on size, shape or other characteristics). She gladly volunteered – in exchange for a free lunch.

A few weeks later, she was surprised when she was the only one in the department asked to donate a second sample. During this same period, she had been offered a full-time position as a trainee and was transferred to the phlebotomy department.

Later in the summer, she was tracked down by Prof. Carl-Bertil Laurell, MD, PhD, the head of the Clinical Chemistry Department at Malmo General Hospital, a part of the University of Lund. Laurell asked her to come to his office for some information. He explained that one of her blood samples had shown an unusual profile in one of the plasma proteins. Later, after another test, he confirmed that Bowling had Alpha-1 Antitrypsin Deficiency and a PiZZ genotype.

She met with Laurell a few more times. He impressed upon her the possible future health effects that Alpha-1 could bring. He also told her about the lifestyle changes she could make to reduce the chance of developing respiratory symptoms as she got older.

According to Bowling, before she came along, Laurell had to receive his PiZZ samples from a patient in Oslo, Norway. To have his samples of Alpha-1 blood plasma come from a few blocks away was quite an exciting prospect at the time.

HELPING TO MAKE HISTORY
At the time, Bowling had no idea just how important Laurell was in the history of Alpha-1 and chronic obstructive pulmonary disease (COPD) in general.

But in fact, Laurell was a pioneer. He was famous for his research, including the co-discovery of Alpha-1 Antitrypsin Deficiency in 1963, along with Sten Eriksson, MD. While still a teenager, Bowling was among Laurell’s early research volunteers for Alpha-1.

When she was 25, she moved to the southern United States. Perhaps surprisingly, the weather wasn’t one of her reasons.

Her reasons were her love for horses and the opportunity to work in a large harness racing stable in Lake Worth, FL. “I had a great passion for the horses. Of course, it was not a stable financial career,” she says, making a little joke, “but it gave me the adventure of a lifetime.”

By Laura Schwarz
ACT Study Coordinator

As a teen in Sweden, this Alpha helped with research of Alpha-1 co-discoverer.
And 35 years later, she still competes in triathlon events.

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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.
KEEPING FIT through running and working out has been a priority most of her life. In 2005, she began training for triathlons. She describes herself as “a vigorous triathlete with a mean breaststroke, a powerful road-cycle and a lousy run.”

GETTING HER MILES IN

She says her current boss is wonderful, often allowing her flexible work hours to make sure she “gets my miles in.” A few samples of how serious Gunilla is about getting those daily miles in:

- A 20-30 mile bike ride up and down the eastern Kentucky hills, often followed by a ½ mile lake swim from May through September.
- One-mile treadmill run plus 20 minutes of elliptical exercise, plus 3-5 hours of weightlifting.
- A 5-6 mile trail run with her dogs, perhaps with a swim afterwards.
- Triathlon training: half-mile lake swim, 16-mile bike ride, plus 5K run (during summer only).

A healthy diet is also part of her daily routine – though she admits to eating some chocolate nearly every day.

About 10 years ago, a pulmonologist looked at her results and told her, “You don’t match this profile! We don’t know what to do with you!” From then, she was referred to the University of Kentucky – only because she was doing so well. Gunilla said her medical testing “caused a bit of confusion, as [the doctors would have normally expected me] to need a lung transplant due to my poor blood work and my age.”

Bowling currently lives with her partner, Tim, and her two sons, both Alpha-1 carriers. Eric, a senior at University of Pikeville, is a business major and plays on the university soccer team. His 84-year-old grandmother, who teaches line dancing at the local senior citizen center, among other activities, is returning to America from Sweden for Eric’s graduation this spring. Alex is a sophomore at the Mayville Community College, working towards a carpentry degree.

Fortunately for Bowling, she decided early in life to heed Laurell’s advice (except for several years in the 1990s when she lived with her first husband’s smoking habit) and has obviously remained healthy and fit. The secondhand smoke made her “horribly sick,” she says. But today, “I am proud to say that I am beating the odds that seemed rather grim when I was a teenager.”

She would like to meet other Alphas in her area and her sons Eric, second from right, and Alex.

Gunilla Bowling with Tim, left, and her sons Eric, second from right, and Alex.

PRECONCEPTION genetic testing concerns

By Sara Wierse, MS, CGC
Medical University of South Carolina

There is a new trend in reproductive medicine. Genetic testing for autosomal recessive* conditions is now being offered to parents to determine if their future children are at risk of having one of these conditions.

Until recently, there was no routine testing of parents to determine who is a carrier of Alpha-1 Antitrypsin Deficiency (Alpha-1). However, one California genetic testing company, Counsyl, has now included Alpha-1 to their panel.

Interested individuals have a blood or saliva sample taken at their doctor’s office and send it to the company. Counsyl tests the sample for many different genetic conditions that may be passed on to a child, including the Z allele for Alpha-1. With appropriate genetic counseling, these families can make important family planning decisions.

The test offered by Counsyl screens for over 100 genetic conditions. This list includes those recommended by the American Congress of Obstetricians and Gynecologists (ACOG) and American College of Medical Genetics (ACMG) as well as others. The use of this testing is making many more people aware of their carrier status for many genetic conditions.

Some experts have questioned the accuracy of the Counsyl screen. The single peer-reviewed study reported so far appeared in Reproductive BioMedicine Online. All the authors were either employees or consultants for Counsyl.

Such screening tests generally do not have to be approved by the Food and Drug Administration.

One disease in which this testing has been accepted for many years is cystic fibrosis (CF). Carrier screening for CF has been standard practice since 2001. In order for a child to be born with cystic fibrosis, both parents must be carriers for the condition. In the Caucasian population, 1 in 25 individuals are carriers for CF. This means that if there is no family history of CF in the family, the chances that a child could have CF is 1 in 2,500. However, if both parents are carriers, the chance is significantly higher. The purpose of screening is to alert families with an increased chance to allow for family planning.

Additionally, different ethnic groups are at a higher risk for having some conditions than others. The Caucasian population is the group at the highest risk for CF, whereas the African American population is at a low risk for CF but a higher risk for sickle cell disease. In the African American population, 1 in 12 individuals is a carrier for sickle cell disease.

Historically, many individuals in the Alpha-1 community never knew about this disease until they, their child or family member was diagnosed as a ZZ. This may happen early in life as a result of poor liver function, or later when an adult is diagnosed with emphysema. The new type of genetic screening allows testing of family members in order to identify those that are carriers, those that are not, and even those that have undiagnosed Alpha-1.

It is quite possible for people to take such a genetic test and find out they have or carry Alpha-1 with no known family history. These people will then have to decide how this information affects them and their health and family planning decisions. Some couples in this situation have reached out to the Alpha-1 community in order to learn more about Alpha-1. While it is unclear what impact, if any, this new test will have on the Alpha-1 community, it is important to be aware of its availability and the possible results that may come out of it. For our part, we can do our best to welcome and educate all newly diagnosed Alphas.

*In autosomal recessive conditions, both parents must be carriers of the condition and each must pass on a disease allele to their child, in order for the child to have the condition. This is not dependent on gender – it affects boys and girls equally.
**Q:** Should I get regular blood tests to check for changes in my alpha-1 blood levels?

**A:** Patients with the carrier state and intermediate levels of Alpha-1 are often concerned that their levels may fall over time to levels that put them at risk. This should not be a concern, because alpha-1 protein levels do NOT deteriorate over time into levels that put patients at enhanced risk. Thus, there is no indication for regular follow-up testing for alpha-1 blood levels in this group.

In fact, serial testing of alpha-1 blood levels is generally not indicated in any form of Alpha-1 Antitrypsin Deficiency.

Blood levels of alpha-1 antitrypsin can change dramatically in individuals with PiMM phenotypes, because alpha-1 antitrypsin is an “acute phase reactant.” That means that blood levels of alpha-1 protein in PiMM individuals, though generally very stable, can double with stresses such as with infections and surgery. However, persons with the PiZZ phenotype show only very minimal changes with such stresses. Thus, screening subjects for low levels of alpha-1 protein can frequently be diagnostic of the homozygous deficiency state, since they are much less prone to false elevations due to stress. Carriers with PiMZ (and less often, PiSZ) types can be more problematic, as they may show near normal levels in times of stress. This explains the importance for genotyping individuals in addition to measuring blood levels.

While PiZZ patients don’t significantly change their alpha-1 protein levels with stress, patients getting alpha-1 augmentation therapy do show wide swings in their blood levels of alpha-1 protein during the days following each infusion. This is because of the sudden boost in the blood concentrations from the protein infusions, followed by the natural redistribution of the infused protein into the tissues, combined with its natural clearance from the body. Thus, in patients receiving weekly intravenous infusions, the timing is everything when interpreting alpha-1 protein levels. The nadir or lowest level, that is, the level just prior to the next infusion, has been shown to provide alpha-1 antitrypsin that is deemed to be at a “protective” level. This nadir level of alpha-1 was documented to be very uniform in individuals in the phase I and II studies done in the 1980s, and therefore does not need to be performed in new patients beginning therapy. Of note, patients receiving Alpha-1 infusion therapy may be misdiagnosed as PiMZ carriers if blood is sent for phenotype (protein) testing while on therapy, has been shown to provide a correction of the antiprotease deficit at both sites: infusion directed at studying this approach as an alternative to the current standard, intravenous therapy.

Aerosol therapy with alpha-1 protein seems logical, but there are some major questions about this approach that still need answers.

First of all, the protease-antiprotease hypothesis, which is the fundamental backbone that supports the idea of augmentation therapy, has limitations. We do not know where the protease burden actually occurs in the lung. Is the injury happening on the airway side, or the blood vessel side of lung airspaces? Intravenous therapy has been shown to provide a correction of the antiprotease deficit at both sites: infusion therapy restores antiprotease activity to both the blood and the airspace.

However, aerosols do a significantly better job of restoring protection to the airspace side of the lung than they do to the bloodstream side. Thus, if the protease burden is actually vascular based, one could imagine that an aerosol source of protection might be at a severe disadvantage and, therefore, may not be effective. Secondly, the lung is an organ that was not designed to have high concentrations of airspace protein, so the long-term effects of giving a purified protein to the lung on a daily basis remain to be tested.

With these concerns aside, an aerosol approach remains a logical alternative, but my own view is that it will need to have documented clinical efficacy before it can replace the current standard of therapy, weekly intravenous infusion therapy.

**Q:** Should I get a mediport for my alpha-1 infusions?

**A:** The decision to get a permanent intravenous access site (commonly called a mediport, portacath, or just “port”) for alpha-1 infusions is one that needs to be made carefully in close consultation with your prescribing physician. It clearly increases the convenience of the infusion process, increases the efficiency of task and may eliminate the pain associated with venipuncture.

But despite clear advantages with respect to the mechanics of giving each infusion, these advantages do come with risks. Central venous access ports create a new danger for blood stream infections and these types of infections can be life threatening when not recognized and treated immediately.

Treatment of central line infections generally includes the need to have the access port removed altogether, and in some instances, weeks of intravenous antibiotics. Another concern is that permanent ports have the potential to form blood clots at the site, which can lead to arm swelling on the affected side and the possibility of blood clots being released into the lungs (although generally not the life-threatening type). These risks need to be balanced against the degree of difficulty present with starting a fresh intravenous access with each weekly or biweekly infusion.

In my own practice, I generally advise against the use of a central venous access for alpha-1 infusions unless the patient finds that intravenous access is very difficult and/or not practical, considering their specific environment. The pros and cons of a port access site need to be addressed on an individual basis with the care team.  

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**Alpha-1 protein levels do not get worse over time. Serial blood tests are not needed.**

**Q:** Why don’t we have an inhaled form of augmentation?

**A:** There is beauty and simplicity in the idea that one might provide the “protective shield” of alpha-1 protein by an aerosol approach to patients with Alpha-1 Antitrypsin Deficiency. The lung is one unusual organ: it can be directly accessed via the mouth and nose, without having to penetrate skin and tissue barriers. It has been shown that one can create theoretically protective levels of alpha-1 protein in the airways and alveolar spaces using an aerosol route. Another advantage is that the expense of intravenous infusion therapy might be lessened, since one could eliminate the potential for “wasteful” dosing of protein to the entire body (muscles, heart, liver, skin etc) by focusing on the organ of interest, the lung. For these reasons there continues to be research directed at studying this approach as an alternative to the current standard, intravenous therapy.

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Clinical Resource Center: Ohio State University carries on NIH Alpha-1 tradition

By Mark D. Wewers, MD
Associate Director, Davis Heart and Lung Research Institute
The Ohio State University

The Ohio State University’s Clinical Resource Center started unofficially in 1982 when James Gadek, MD, was recruited to direct the pulmonary program here. Our resource center began as an outgrowth of the foundational studies performed at the Clinical Center at the National Institutes of Health (NIH). At the NIH, Gadek was responsible for infusing the first purified preparations of human alpha-1 antitrypsin into patients under the direction of Ronald Crystal, MD, then chief of the Pulmonary Branch. (This research appeared in the Journal of Clinical Investigation, 1981.) Gadek’s work opened the door to the concept that alpha-1 augmentation therapy could become a realistic treatment option.

Gadek, Biologicals, a subsidiary of Miles Laboratories, then took that idea one huge step forward by developing a commercial product, also studied at the NIH under Crystal’s guidance. I was excited to be given the chance to direct this study, which provided the basic proof of principle that infusion therapy could be a practical treatment option. This research appeared in the New England Journal of Medicine in 1987. Gadek then recruited me to Ohio State to join him in the study of Alpha-1 patients, broadening the NIH connection to Ohio State.

The Registry was initiated in 1987 and involved 37 participating centers. Ohio State joined the ranks of these centers that provided uniform approaches to pulmonary function testing. We were able to contribute 26 patients to the study, which demonstrated the safety of the approach and provided the FDA with the necessary information to support the continued licensing of infusion therapy. (This study was reported in the American Journal of Respiratory and Critical Care Medicine in 1998.) Inspired by the Registry initiative, Ohio State has continued to provide a resource to Alpha-1 patients in the Midwest region. Our center gives guidance and monitoring for affected adults and family members seeking advice on the implications of having Alpha-1 Antitrypsin Deficiency.

Recently, our program has begun to investigate novel concepts to provide insight into the mechanisms whereby Alpha-1 leads to loss of lung cells (emphysema). My colleague Anasuya Sarkar, PhD, recently funded through the Alpha-1 Foundation, is investigating the hypothesis that the lack of alpha-1 antitrypsin in the blood serum may contribute to the enhanced generation of a molecule called LL37. The hypothesis to be tested is that LL37 levels may be higher in the deficiency state and that this increase may predispose affected lungs to injury and tissue loss over time.

We are hoping to recruit individuals from our Clinical Resource Center to obtain blood samples to test this idea. If confirmed, the hypothesis might explain why Alpha-1 related emphysema is more prominent in the bottom of the lung, where we expect the LL37 to be increased. More importantly we hope to open two new avenues for preventive treatments for the lung disease.

The Ohio State program has greatly expanded its capacity to help Alphas as well as all patients suffering from the consequences of emphysema. Philip Diaz, MD, has developed a severe lung disease clinic in the university Lung Center that addresses the complex needs of patients with severe chronic obstructive lung disease. Under his guidance, Ohio State was one of the lead recruiting centers in the National Emphysema Treatment Trial (NETT), which tested the effectiveness of lung volume reduction surgery. Diaz’s program now studies the effect of long-term oxygen treatment for patients with emphysema as one of the top recruiting centers for the NOTT (Nocturnal Oxygen Treatment Trial). This study should provide important practical information about the usefulness of oxygen supplementation in patients with moderately severe hypoxemia.

Thus, the initiatives that began in the Pulmonary Branch of the National Institutes of Health are alive and well in the Ohio State Lung Center. We are excited to be able to provide continued service to those individuals with Alpha-1 and offer a broad range of support structures through the Clinical Resource Center and the additional support structure of the Lung Center. We hope to add to the knowledge of the mechanisms of disease as the search for effective preventive measures continues here and elsewhere.
Drug may improve liver disease in Alphas with advanced cirrhosis

By Charlie Strange

Dear Registry Members,

Increasingly, many members of the Alpha-1 scientific community believe that treatments directed at the liver will be important for both lung and liver disease.

The study below is targeted at individuals with very advanced liver disease. I believe this study is important because we need to figure out if an inexpensive medication can improve liver disease in Alphas with cirrhosis. Future studies will also evaluate the current study design to see if this model is an effective measure of cirrhosis improvement.

Several changes in this trial have made it much easier for Alphas to take part. Please consider participation.

Vital research studies need Alpha-1 volunteers

REGISTRY DIRECTOR’S INVITATION

By Charlie Strange

The only way to develop new treatments and therapies for Alpha-1 is to study individuals with disease. The more that we understand about the changes that occur in the body, the more we will be able to effectively treat those changes. The lung is filled with arteries and vessels that carry blood to be oxygenated and blood that has already been oxygenated to send to other parts of the body. Researchers are wondering if Alpha-1 causes changes to those blood vessels that we could target with new therapies that could prevent the progression of the disease.

Some reimbursement ($120 + parking and lunch) is available for travel expenses. Call (212) 395-9821 for information, or if you would like to participate.

Why should you participate?

Preliminary Study of the Efficacy and Safety of Carbamazepine in Severe Liver Disease Due to Alpha-1-Antitrypsin Deficiency

This is a double-blind, placebo-controlled trial directed by David Perlmutter, MD, of the University of Pittsburgh Medical Center. In this trial, 20 subjects will receive carbamazepine and 10 subjects will receive the placebo (a capsule that looks identical but does not contain carbamazepine). Double-blind means that neither the research subject nor the research team know which person is receiving active medication or placebo.

The clinical trial is based on the laboratory findings that carbamazepine reverses liver damage and scarring in a mouse model of Alpha-1 Antitrypsin Deficiency. This trial is also possible because this drug has been used safely for many years in the treatment of epilepsy, chronic pain and depression.

The results of the trial will be revealed through liver biopsy and liver pressure determinations, done at the beginning and end of the trial. Liver biopsy and pressure determinations 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 a dose which is identical to the one that is used for epilepsy or mood stabilization. It will be started at a lower dose and slowly increased over the first four weeks to reduce the likelihood of any allergic reaction. The study is taking place at the University of Pittsburgh Medical Center as a single center trial with relatively frequent visits in the first year and a few visits for follow-up in the second year.

There are five visits in the first eight weeks; five additional visits in the remainder of the first year; and three visits in the second year. Funds are available to cover travel expenses. To be eligible for the trial, you must have complete Alpha-1 Antitrypsin Deficiency with signs of elevated liver pressure, among other criteria. Your doctor will be contacted to find out if you meet the entry criteria.

The trial is supported by grants from the National Institutes of Health and Novartis Institute for Biomedical Sciences and has been approved by the Institutional Review Board of the University of Pittsburgh.

For more information or to participate, contact Erin Sandene at erin.sandene@chp.edu or at (412) 692-6558.

For more information or to participate, call (212) 395-9821 for information, or if you would like to participate.
Calendar of coming events

For the most up-to-date listings, check our website at [www.alpha-1foundation.org](http://www.alpha-1foundation.org).

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<tbody>
<tr>
<td>Jan. 24</td>
<td>An Evening at Romeo’s</td>
<td>Miami, FL</td>
<td>Shaefer Withers: <a href="mailto:swithers@alpha-1foundation.org">swithers@alpha-1foundation.org</a></td>
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<td>Feb. 2</td>
<td>Education Day</td>
<td>Gainesville, FL</td>
<td>Alexis Arilies: <a href="mailto:aartiles@alpha-1.org">aartiles@alpha-1.org</a></td>
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<td>Mar. 9</td>
<td>Celtic Connection</td>
<td>Boston, MA</td>
<td>Bob Healy: <a href="mailto:bobhealy125@msn.com">bobhealy125@msn.com</a></td>
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<td>Mar. 23</td>
<td>Education Day</td>
<td>San Antonio, TX</td>
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<td>April 20</td>
<td>Hero Walk</td>
<td>Henrico, VA</td>
<td>Pam Van Scoy: <a href="mailto:vaalpha1herowalm@yahoo.com">vaalpha1herowalm@yahoo.com</a></td>
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<td>April 20</td>
<td>Alpha-1 Research, UMASS</td>
<td>Worcester, MA</td>
<td>Angela McBride: <a href="mailto:amcbride@alpha-1foundation.org">amcbride@alpha-1foundation.org</a></td>
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<td>April 26</td>
<td>Celebration of Life</td>
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<td>April 29</td>
<td>Golf for a Cure</td>
<td>Jacksonville, FL</td>
<td>Sarah Johnson: <a href="mailto:sarah_shirk@comcast.net">sarah_shirk@comcast.net</a></td>
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<td>May 11</td>
<td>George Washington Bridge Walk</td>
<td>New York - New Jersey</td>
<td>Joe Reidy: <a href="mailto:joereidy@verizon.net">joereidy@verizon.net</a></td>
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<td>May 18</td>
<td>Alpha-1 Walk</td>
<td>Philadelphia, PA</td>
<td>Angela McBride: <a href="mailto:amcbride@alpha-1foundation.org">amcbride@alpha-1foundation.org</a></td>
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<td>May 20</td>
<td>Alpha-1 Research Awards ATS</td>
<td>Philadelphia, PA</td>
<td>Angela McBride: <a href="mailto:amcbride@alpha-1foundation.org">amcbride@alpha-1foundation.org</a></td>
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<td>June 7-9</td>
<td>22nd National Education Conference</td>
<td>Washington, DC</td>
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<td>August 10</td>
<td>Education Day</td>
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<td>Nov. 16</td>
<td>Education Day</td>
<td>Anaheim, CA</td>
<td>Alexis Arilies: <a href="mailto:aartiles@alpha-1.org">aartiles@alpha-1.org</a></td>
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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 Antitrypsin 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.

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