We’ll help you talk to your family about testing

Letter from the Director

WELCOME to this edition of the Registry Newsletter. It is an exciting time at the Alpha-1 Research Registry, where several studies have completed and others are starting up. There is a way for everyone to be involved and we want to thank those of you who have chosen to participate in research. This is the most crucial way that people with Alpha-1 can work toward improved treatments and a cure.

I would like to thank Deirdre Walker, our former Research Registry Coordinator, and wish her the best in her career transition to a clinical research management organization. We appreciate her four years of dedication to the Alpha-1 community. We would also like to thank Alysha Carlos, who served as interim Research Registry Coordinator.

We are pleased to have Eryn Varano accept the position of Research Registry Coordinator. Eryn has been a research coordinator at MUSC for several years, studying ways to reduce preterm birth and low birth weight babies in the South Carolina Medicaid population. When that research project was complete, she became available to join the Alpha-1 team. Eryn received her bachelor’s and master’s degrees in social work from the University of Pittsburgh.

Eryn looks forward to growing the Registry programs. Please welcome Eryn as you join or update your Registry information.

An important initiative of the Research Registry and the Alpha-1 Foundation this year is reminding Alphas to talk to their families about testing. Most people living with Alpha-1 have not been tested, and we can help to change this. In this edition, you will read more about family testing and resources, and how we can support you in talking with your relatives. We continue to offer free and confidential Alpha-1 testing through the ACT Study at MUSC, so be sure to let your family members know.

As we expand our outward reach to our families and global communities, new research is homing in on molecular contributions to Alpha-1-related disease, including genomic and inflammatory markers. You will read about important molecular research on Alpha-1 biosamples in this edition. Additionally, new Alpha-1 clinical guidelines were published in 2016 and this edition tells you how you can access these guidelines and share them with your healthcare teams.

As always, we welcome your phone calls and emails. Please let us know if we can help you or your family. Thank you for engaging in Alpha-1 research.

Sincerely,

Charlie Strange, MD,
Director, Alpha-1 Foundation
Research Registry and ACT Study
It’s All in the Family

We can help you talk with your family about testing

By Kimberly Brown
Gene ti c Counselor

This year, the Alpha-1 Research Registry wants to focus on our families. Family history is so important that the Surgeon General encourages families to talk about and write down the health problems that occur in the family. “Doing so may lead to longer, healthier lives together,” the Surgeon General says, and we agree.

Alpha-1 is an inherited condition that is caused by mutations in a single gene. On average, we share half of our genes in common with our parents, siblings and children. If you have abnormal genes for Alpha-1, your family members should be offered testing because they may have abnormal Alpha-1 genes, too.

Alpha-1 is an extremely variable condition, meaning that different people with Alpha-1 can be affected in very different ways. Whether and when Alpha-1 causes you to have lung or liver disease is also influenced by other factors, including your environment — smoking history, lifestyle and exposures — and likely influenced by other modifier genes as well. Beyond sharing genes, families often share a household environment and habits that affect health and health risks.

There may be benefits to testing for Alpha-1, whether you have symptoms or not. For a person with symptoms, an Alpha-1 diagnosis provides an explanation and guides the medical treatment plan. For a person without symptoms, steps can be taken to stay healthy, and to catch symptoms early if they develop. Anyone who tests for Alpha-1 gains information that may be helpful in family planning and can be used to help family members understand the genes in the family. Some relatives who test may receive normal results — showing that they don’t have abnormal Alpha-1 genes. This may relieve anxiety and be good news for future generations. All relatives are invited to test, and testing is strongly recommended for full siblings of people with severe Alpha-1 deficiency (e.g. ZZ, SZ).

The Alpha-1 Coded Testing (ACT) study offers free and confidential home-based testing for Alpha-1. ACT testing is part of a research study that helps us better understand Alpha-1 and barriers to genetic testing. People age 18 and over who

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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.
would like to request an ACT kit may do so by filling out the required informed consent and questionnaire at Alphaoneregistry.org. Children may be tested by a parent's request. Call 1-877-886-2383 to learn more about the ACT study. Alpha-1 testing may also be ordered by a physician or as part of some prenatal genetic screening.

Although testing is easy, some people have hesitations or questions about testing for Alpha-1. The Alpha-1 Foundation is here to help. A brochure about family testing, It's All in the Family, and a family awareness video are available at www.alpha1.org for you to view and share.

We know that every family is unique. I am available to discuss personalized testing recommendations and options for you and your family. Genetic counseling helps each person make informed decisions about testing, and assists people with understanding their results and any next steps when testing is complete. Alpha-1 genetic counseling is free and confidential before or after testing. I can be reached at 1-800-785-3177.

We encourage you to take this year to talk to your relatives about Alpha-1 and other health conditions in your family. You might even log your family information at the Surgeon General's "My Family Health Portrait" page: alf.org/family-history-tool to create a family tree that lasts.

THE ALPHA-1 STAFF of the Medical University of South Carolina gathered recently at an awards event. Front row, from left, Tatsiana Beiko, MD, MUSC clinical instructor; Gwen Blanton; Laura Schwarz, Alpha-1 Coded Testing (ACT) study program coordinator; Alison Garbarini; and Alysha Carlos, who recently left MUSC after serving as Research Registry interim coordinator. Back row, Charlie Strange, MD, director of the Alpha-1 Research Registry and the ACT study; and Suchit Kumbhare. Blanton, Garbarini, and Kumbhare are all Alpha-1 research coordinators.
How about another sample of blood for research?

By Charlie Strange, MD
Registry Director

Why do doctors and researchers always want more blood? The simple answer is that there are at least 5,000 different proteins circulating in the bloodstream. In addition to full proteins, there are fragments of proteins that have been broken or modified, segments of proteins that come from the bacteria that live in our intestines, and pieces of our body that are not proteins, all circulating in the blood. These chemicals are always changing in concentration, and often binding to each other in an hour-to-hour process that helps regulate critical functions of the body.

In Alpha-I, one of the proteins is in low concentration. The alpha-I antitrypsin protein is important because it serves a protective role in the lung. Therefore, the body is unable to prevent injuries to the lung, such as those that occur with smoking, dust, fumes and some occupational exposures. That allows emphysema (holes in the lung) and bronchiectasis (airway walls that are injured and dilated) to develop. One way to make the diagnosis of Alpha-I Antitrypsin Deficiency (Alpha-I) is by the low level of this protein in a blood sample.

But what happens to the other 4,999 proteins in the body of a person with Alpha-I? Can blood tests help us to figure out why some people get severe emphysema and others have normal lungs?

The study of proteins is a 50-year-old science called proteomics.

Fifty years ago, scientists measured each protein of interest in a separate test that was developed specifically for that protein. Twenty years ago, the technology advanced sufficiently to develop antibodies for almost every protein known. Ten years ago, the technology allowed multiple antibody tests to happen simultaneously on a very small amount of blood. Most recently, new technology allows the simultaneous measurement of more than 1,000 proteins in a single blood sample. We hope we will soon be able to see results from these advancements in technology.

What should you do with all the extra test results? Should you sit with your doctor and try to understand all 1,000 proteins — and why one or another is high or low? Clearly not.

We need to figure out which proteins are important, either alone or in combination, to keep people healthy. For this research, we use blood samples before and after medical interventions are performed. Comparisons can also be made between people with different symptoms or severity of the disease to make important conclusions.

Recently, a valuable blood resource was sitting at the National Institutes of Health and not being used. The blood samples were collected from 1987 to 1994 as part of the “National Heart, Lung, and Blood Institute (NHLBI) Registry of Individuals Severely Deficient in Alpha-I Antitrypsin.”

Of the 1,129 people who enrolled in the NIH Registry, more than 600 still have blood samples that have been kept in -80 degree Centigrade freezers for almost 25 years. These samples are now at the Medical University of South Carolina in Charleston and available for collaborative projects in the Alpha-I community.

An accurate history of the donor is critical to any blood sample. Luckily, the NHLBI Registry followed these participants for many years and we have a record of this participation in the current Alpha-I Foundation Research Registry.

Blood samples are important. Because it is impossible to know where the cure for Alpha-I will emerge, our community continues to build the tools that tomorrow’s science needs to better understand human biology.

Some of you were contributors to this valuable NHLBI blood repository 25 years ago. We thank you for your contributions to science!
The switch from lab-only science to working with people

By Gwen Blanton
Research Coordinator

From a very young age, I knew I wanted a career in medicine. I was drawn to the science of it and felt the urge to help those suffering and in need, but I wasn’t sure which discipline would fit me best.

After completing my undergraduate degree, I accepted a job in a basic science research laboratory focusing on lung cancer. I was nervous and excited to dive in and get to work in the lab. It was there that I began to develop the skills I would build on throughout my career. In biomedical research, funding is never guaranteed, so, over the years, I’ve worked in several different labs, always learning new techniques and expanding my medical knowledge.

My pull toward the clinical side began while I was working in a laboratory that did both bench science (science done strictly in a lab) and clinical research (working with people). I processed and analyzed all the clinical trial patient samples that came through our lab. I started noticing changes and trends on paper, while becoming more and more curious about how laboratory numbers translated to real-life changes in patients.

I stepped out of my lab comfort zone when an opportunity arose for me to move into fully clinical research.

The position was in pulmonary medicine, working in clinical trials for COPD and Alpha-1 Antitrypsin Deficiency. I knew very little about Alpha-1 going in, but was excited to work directly with patients and learn more about this genetic condition.

The initial shift was a little bumpy (who knew there could be so much paperwork?), but it was the single best decision of my career.

My science research background helped me put my knowledge to use and underscored the importance of clinical trials. I understand the science leading up to the clinical application because I’ve been there and done that work. I know why we conduct the tests, because I can follow things at the molecular and cellular levels. Working with patients has given me a special appreciation of how all of this applies to them specifically.

In a very short time, I’ve learned a lot about the diseases of Alpha-1, the alpha-1 protein, and the ever-growing list of genetic mutations associated with Alpha-1. This knowledge is important when I’m enrolling people into the Alpha-1 Research Registry and clinical trials. My patients are more than statistics on a page or numbers in a lab — they’re people who depend on me.

The Alpha-1 community accepted me with open arms, and I’m so grateful for that. This position is equal parts challenge and reward, and that’s how I know I belong here. Every step in my career has led me here, to this team with a unified goal of doing everything we can to better the lives of those who suffer from Alpha-1.

From working as a bench science researcher in the past to a clinical coordinator now, I have seen how patients teach scientists — what works and what is needed — and how science helps patients receive better treatments and care.

I remind all of you with Alpha-1 that engaging in research is a way to work toward your own cure. It can’t be done without you. Understanding your experiences, your data and your outcomes is how breakthroughs, and one day a cure, will be reached.

I hope to be a part of the fight for that common goal for years to come.
A panel of Alpha-1 specialists from across the country published “The Diagnosis and Management of Alpha-1 Antitrypsin Deficiency in the Adult” in July 2016. Guidelines are intended for healthcare practitioners and they are important because they recommend best medical practice for all diseases.

Guidelines must be evidence-based to be accepted by the medical community, and evidence comes from past clinical trials and publications. When a question has not been studied and comprehensively answered, any opinion is incomplete. Clinical practice guidelines for Alpha-1 are particularly difficult to assemble since so many aspects to optimal care remain unknown or based on expert opinion alone.

The full guidelines were published in the Journal of the COPD Foundation. You can read them at a1f.org/clinical-guidelines. The first page is a one-page summary of recommendations. This is an easy-to-read guide to share with your doctors who want to learn more about Alpha-1.

Most recommendations did not change since the last guidelines in 2003, such as these: Everyone with COPD, unexplained liver disease, panniculitis or unexplained bronchiectasis should be tested for Alpha-1. Most family members should be offered testing for Alpha-1.

One new action point is the recommendation for a baseline chest CT scan in newly diagnosed patients who are symptomatic and/or have abnormal pulmonary function on spirometry. Sometimes emphysema can be seen on a CT scan, even in people with normal spirometry. Establishing a baseline representation of lung disease by CT scan can help to track disease progression later. However, regular CT scans for people with Alpha-1 are not recommended.

The panel also evaluated the available data about Alpha-1 augmentation therapy and dosing. Augmentation therapy is recommended for people with Alpha-1 who have a forced expiratory volume in 1 second (FEV1) less than or equal to 65 percent. For those with Alpha-1 lung disease but a higher FEV1, the recommendation is “a discussion with each individual regarding the potential benefits of reducing lung function decline with consideration of the cost of therapy and lack of evidence for such benefit.”

There is no current evidence that increasing the weekly dose above the current FDA-approved dose provides any added benefit. People for whom augmentation therapy is not recommended, such as those who have received a liver transplant, are also outlined in the new guidelines.

Alpha-1 Antitrypsin Deficiency is an uncommon disease. This makes large clinical trials to answer scientific questions more difficult. For that reason, close collaboration among doctors, researchers and the Alpha-1 patient community are essential.

Since there are many unanswered questions in Alpha-1, the new guidelines serve both as recommendations for today’s best practices and as a roadmap of work that is needed to better understand the diseases of Alpha-1.

For people living with Alpha-1, please continue to support and participate in Alpha-1 research. Research is the pathway to stronger evidence and better treatment in the future.
# Alpha-1 Word Search

<table>
<thead>
<tr>
<th>International</th>
<th>Guidelines</th>
<th>Sequencing</th>
<th>Biosample</th>
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<td>Registry</td>
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<tr>
<td>Family</td>
<td>Alpha</td>
<td>Gene</td>
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</tr>
</tbody>
</table>

Answer key is on page 8.
The MZ Carrier Genomics Study finishes enrollment — more to come

By Kimberly Brown
Gene Counselor

The Alpha-1 Carrier Genomics study has completed enrollment. The research team at Medical University of South Carolina (MUSC) thanks the 104 people who participated.

This was an important study to better understand why some people with the MZ genotype (often called carriers) develop COPD, while many others do not. All participants had previous MZ results with an alpha-1 protein level in the lower quartile for the MZ genotype. They all answered questions about their lung symptoms and submitted blood samples for advanced Alpha-1 testing by gene sequencing.

Gene sequencing spells out the DNA sequence of the Alpha-1 genes and is an advanced test that is not needed to detect most cases of Alpha-1. Yet sequencing findings are important for some. In fact, six percent of participants received sequencing results that may impact their risk for Alpha-1 symptoms or their medical management. Because sequencing can be costly, and is usually not necessary, the research team will use this data to consider how to increase detection rates in cost-effective ways.

Genomic variants — changes in the DNA sequence that can be detected by sequencing — make each person unique. Each person has many variants across the genome. The Alpha-1 gene is just one of over 20,000 genes that make up the human genome. Some genomic variants raise a person’s disease risk, while other variants are neutral (no effect) or even lower a person’s risk. Variant interpretation is an important and intricate part of personalized medicine.

People in this study received their personal lab reports in September 2016, and the MUSC research team is continuing to study the large amount of alpha-1 gene sequence data from the study group as a whole. This process involves working with bioinformatics specialists to see if particular variants in certain areas of the alpha-1 gene may correlate with COPD. For example, researchers wonder if variants in part of the gene called the promoter region might correlate with presence of lung symptoms. Although this work is preliminary, findings will guide future research.

Learning more about who may benefit from sequencing, and the significance of sequence variations in the Alpha-1 gene, are important steps toward improving Alpha-1 detection and better understanding the risks and best treatment for each specific person. We will publish and share the results of the ongoing analysis with the Alpha-1 community when they are complete.

We hope to have more studies soon for people identified as MZ in lab tests. We encourage anyone with abnormal Alpha-1 genes to join the Research Registry and view current studies at Alphaoneregistry.org.

Alpha-1 Word Search

International Guidelines Sequencing Biosample Awareness Allergist Registry Testing • Support Leader COPD Family Alpha Gene
Laura Schwarz receives MUSC employee of the quarter award

Laura Schwarz, program coordinator for the Alpha-1 Coded Testing (ACT) trial, received the Medical University of South Carolina (MUSC) employee of the quarter award in November 2016.

Laura has served the Pulmonary Division at MUSC for 18 years, and has been coordinating the ACT study for 12. She is well known in the Alpha-1 community for helping so many people online and by telephone, and for attending education days and the Alpha-1 National Education Conference for many years. You may also know Laura from her articles in this newsletter.

Over 30,000 people have enrolled in the ACT study, and “Laura has handled every one of these test kits, aligning letters of results with the laboratory findings,” her nomination reads. “She is meticulous in her job and dedicated to those who enroll. Laura is the voice on the telephone for the Alpha-1 community to discuss testing.”

Her nomination continues:

“Laura is the heart and soul of this important national testing program. She really cares about each and every family that requests test kits from MUSC. I am convinced that Laura’s kind voice and soft-spoken demeanor is a calming influence on families who are under the stress of family genetic testing.”

Laura has also been, and will continue to be, a mentor to the younger research coordinators in the Alpha-1 laboratory. MUSC is proud to have her dedication and expertise. Please join MUSC in recognizing Laura’s exceptional service and accomplishments!

Congratulations, Laura!

Don C. Rockey, MD, chair of the Department of Medicine at the Medical University of South Carolina, presents the employee of the quarter award to Laura Schwarz.
Wanted — Alpha-1 support group

By Laura Schwarz
ACT Program Coordinator

“We desperately need a support group in Northern Ohio and I am willing to lead it!” said an enthusiastic Alpha at the Pittsburgh Education Day last September. I jotted her name down on my napkin at the Friday night dinner. Later, I passed on the information to Barbee Bennington, the Foundation’s support group and program coordinator.

Currently there are more than 80 Alpha-1 support groups around the country and many states have multiple groups. Many of these groups have leaders who go above and beyond the required duties of a support group leader by volunteering their time and effort to serve the Alpha-1 community in many ways.

I’m sure there are Registry members who have thought about organizing a support group, but for various reasons haven’t moved forward with the idea.

Bennington outlined the in-depth information below about support groups and their leaders:

The main advantage of the Alpha-1 Foundation’s support group program is that the leader of every group knows Alpha-1 personally. Most are lung or liver-affected Alphas, a family member of an Alpha, or, in a couple of cases, a respiratory therapist.

Many of these leaders have lived through the same things that most newly diagnosed Alphas experience, and they have learned to adjust their lifestyles to live fulfilling lives.

“Support group leaders provide support, education and a safe haven for Alphas to meet each other,” Bennington said. “The leaders of these groups work hard on everyone’s behalf. Half of our leaders work full-time jobs, are going to school, are raising families or are caregivers. Most receive Alpha-1 augmentation therapy and deal with exacerbations and testing. Some go through transplant evaluation and transplantation. They come from all walks of life; have a wide variety of abilities, education and financial status. All are embedded into the communities they serve. Their dedication is outstanding. They are the heart and soul of the Alpha-1 community.”

Potential support group leaders go through a training process to enhance their success. This includes completing an application and being interviewed by Cathey Horsak, the Foundation’s director of community programs.

“Before their first meeting,” Bennington says, “they are trained on how to run a support group, educated about the Foundation’s programs and resources, and taught about Alpha-1 through instructional videos from Clinical Resource Center physicians who are experts on the condition.”

Last but not least, new leaders are encouraged to join the Alpha-1 Research Registry.

If you attended last year’s Alpha-1 National Education Conference in Miami, you may have met Richard Lovrich. Diagnosed as an Alpha in 2011, Lovrich received the Claude Baril Communications Award at the 2016 conference.

Lovrich is also the leader of a new support group in upstate
New York. The group’s first meeting was in November 2016. Lovrich received help from Bennington and the Foundation to locate Alphas to invite. He also contacted his own doctor’s medical practice, other physicians and groups and used social media to find more people to join the group.

For the group’s meetings, Lovrich chose his main workplace — Proctors, a theater complex hosting everything from touring Broadway plays to comedy routines, music and movies. This group is probably the only one that can take in a Broadway show following the meeting!

Lovrich believes that he made the right decision in forming the Capital Region Alpha-1 Support Group. Although his career — as the creative director of Proctors in Schenectady, Universal Preservation Hall in Saratoga Springs and Capital Repertory Theatre in Albany — requires a great deal of his time, he points to the old truism that “the busiest people are the best people to take on more.”

His background in professional photography also led him to assist the Alpha-1 Foundation by photographing at Education Days and other events, notably the 2015 FDA public meeting on patient-focused drug development in Silver Springs, Maryland. “I enjoy a busy lifestyle,” he says, “sometimes interrupted, but never derailed, by Alpha-1.”

Lovrich gave a talk at his first meeting that included this quote from Anne Frank:

“How wonderful it is that nobody need wait a single moment before starting to improve the world. Well, this is our moment,” he added.

If you are interested in forming an Alpha-1 support group in your area, call Barbee Bennington at 855-351-6610.

Clinical Resource Centers, support groups team up

Support groups bring together both newly-diagnosed Alphas and experienced Alphas to share their stories, express fears, and to learn more through planned programs featuring Alpha-1 expert speakers, including doctors from their local Alpha-1 Clinical Resource Center (CRC).

These experts offer Alpha-1 education both to the patient and physician community. Specifically, they have made a commitment to engage and support the Alpha-1 community directly through the support groups.

For Frank Loutsch, 53, of Cedar Rapids, Iowa, it is both sharing and what he continues to learn that makes his support group so valuable to him. His support group works with Jeff Wilson, MD, a lung specialist at the University of Iowa.

“Recently we had a woman in our group who had been told she would need a lung transplant,” says Loutsch. “And at our next support group meeting we had a transplant expert speak. That [talk] pretty much made the decision for her — she scheduled the transplant. That was a year ago, and today she is doing well.” Loutsch says everyone in the group benefited from sharing in that experience with her.

Timothy Craig, DO, of the Penn State University CRC, takes this commitment seriously. He works regularly with the Southeast Keystone Alpha-1 support group.

“I see it as my role to not only help bring in speakers, but to attend or have one of my colleagues attend support group meetings, so that one of us can facilitate discussions,” he says. “The friendship and comradery that develops helps people feel like they can open up. The sharing helps lower a person’s fears about their own future.”

A longer version of this article appears in the Spring 2017 issue of Alpha-1-To-One magazine. To find out if there is a support group or Clinical Resource Center near you, visit alpha1.org.
## Calendar 2017

### Building Friends for a Cure Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Name</th>
<th>City, State</th>
<th>Contact &amp; Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apr. 10</td>
<td>Golf for a Cure</td>
<td>St. Augustine, FL</td>
<td>Richard and Sarah Johnson, <a href="mailto:qqjigq@comcast.net">qqjigq@comcast.net</a></td>
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<td>Apr. 22</td>
<td>Hero Walk</td>
<td>Richmond, VA</td>
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<td>May 13</td>
<td>George Washington Bridge Walk</td>
<td>NY/NJ</td>
<td>Joe Reidy, <a href="mailto:joreidy@verizon.net">joreidy@verizon.net</a></td>
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<tr>
<td>June 10</td>
<td>Step Forward for Alpha-1 Iowa</td>
<td>Johnston, IA</td>
<td>Peg Iversen, <a href="mailto:pegivers@mcbsi.com">pegivers@mcbsi.com</a></td>
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<tr>
<td>Sept. 22-24</td>
<td>Escape to the Cape 2017</td>
<td>Cape Cod, MA</td>
<td>Angela McBride, an <a href="mailto:McBride@alpha1.org">McBride@alpha1.org</a></td>
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For more information about Building Friends for a Cure, contact Angela McBride, (877) 228-7321, ext. 233 or an McBride@alpha1.org

### Education Days

<table>
<thead>
<tr>
<th>Date</th>
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<tr>
<td>March 25</td>
<td>Austin, TX</td>
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<tr>
<td>May 6</td>
<td>Atlanta, GA</td>
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<tr>
<td>August 5</td>
<td>Boston, MA</td>
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<tr>
<td>Sept. 30</td>
<td>Boise, ID</td>
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<tr>
<td>Oct. 21</td>
<td>New York/New Jersey</td>
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</table>

**National Education Conference**

June 23-25 Chicago, IL

For more information about Education Days or the National Conference, contact Kim Caraballo, (877) 228-7321, ext. 323 or ycarballo@alpha1.org

### Special Events

<table>
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<tr>
<th>Date</th>
<th>Event Name</th>
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<tr>
<td>March 30</td>
<td>Anchors Away for Alpha-1 — Naples, FL</td>
<td>Naples, FL</td>
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<tr>
<td>April 30</td>
<td>Celebration of Life Dinner — Miami, FL</td>
<td>Miami, FL</td>
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<tr>
<td>May 1</td>
<td>Celebration of Life Golf Classic — Miami, FL</td>
<td>Miami, FL</td>
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For more information about these events, contact Jeannine Kushner, (877) 228-7321, ext. 204 or jkushner@alpha1.org

### Virtual Support Group Calls

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>May 30</td>
<td>Update on Current Clinical Trials and Research Registry Update with Charlie Strange, MD, Director of the Alpha-1 Foundation Research Registry</td>
</tr>
</tbody>
</table>

To participate: At 9 pm Eastern, dial: 1-800-920-7487. When prompted, enter the code: 9335 9985#

For more information about upcoming events and support group meetings, please visit the calendar at alpha1.org or call us at (877) 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 $65 million to support Alpha-1 Antitrypsin Deficiency research and programs at 106 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 therapeutics.

The Registry Update is funded by unrestricted educational grants from:

**AlphaNet, CSL Behring and Grifols**