



ALPHA-1
FOUNDATION

RESEARCH REGISTRY



MUSC

MEDICAL UNIVERSITY
of SOUTH CAROLINA

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UPDATE

Making a better Registry



Letter from
the Director

considered changing the way Registry data is collected. Some of the questions we have been asking:

Is it possible to have Registry participants visit one of the Alpha-1 Foundation Clinical Resource Centers (CRCs) once a year to enter accurate data into the Registry with the help of a research coordinator?

And if we are going to the trouble to get participants to a CRC, do we want to collect CT scans and blood to serve as a useful resource for investigators?

Should we perform spirometry or other breathing tests at these visits? Why not collect the entire DNA sequence, too?

Do the researchers who study Alpha-1 really need all the tools that the Alpha-1 Foundation would spend hard-earned dollars to collect?

The answers to these questions depend on finding a balance between the resources of the Alpha-1 Foundation and the likelihood of finding a cure by use of these resources. Those of us who saw the film *Field of Dreams* believe that if we build this resource, then the researchers will come.

So as we move into the testing phase of this brand new world, the

Registry staff plans to keep our eyes on the ball. An article in this issue by Mike Graves, our Registry coordinator, describes the optimal design of the Registry. We have begun a three-way conversation with lung and liver researchers, the Foundation staff, and the Alpha-1 community to find the right balance between the time and money required to collect useful data, and the likelihood that a researcher will use these resources to advance towards a cure.

We also hope to build a resource that can help to unify similar Alpha-1 registries in other parts of the world. As always, we welcome your emails, your suggestions and support and thank you for your participation in the Alpha-1 Foundation Research Registry. Let's hit this initiative out of the park.

Sincerely,

Charlie Strange

Director, Alpha-1 Foundation
Research Registry

Professor of Pulmonary

and Critical Care Medicine

Medical University of South Carolina

WELCOME to the spring 2012 Alpha-1 Foundation Research Registry Newsletter. In this edition we will focus on the design and usefulness of the Registry. For some years, the staff at the Registry has worked diligently to collect the best possible information on Registry participants. However, all researchers know that some information about genes and complicated medical tests is difficult for Alphas – or anyone who is not a healthcare professional – to get exactly right. Wrong information in the Registry can lead to missteps and duplication of effort to make sure the information is corrected before reporting medical outcomes.

Therefore, for some time, the Alpha-1 research community has

The Future of the Alpha-1 Foundation Research Registry

By: Mike Graves



The Alpha-1 Foundation Research Registry has been promoting research throughout the Alpha-1 community for over a decade. The Registry has enrolled more than 4,200 Alphas and carriers of the Alpha-1 gene since 1997 and assisted in 84 research studies. The purpose of the Registry is to match the appropriate Alphas and carriers with current research projects in an attempt to develop Alpha-1 treatments and an eventual cure.

While we plan to continue the current structure of the Registry, we also want to meet the needs of researchers, who have been asking us for additional and more accurate data from the Registry for some years. That's why we have begun to build

Resource Center near their home where they could visit an Alpha-1 expert yearly; and Registry data can be more complete and accurate.

HOW A CRC REGISTRY WOULD WORK:

The Medical University of South Carolina will provide the database to cross-index all the information that accumulates through the coming years.

We also need an easy-to-use tool to gather all this information. Fortunately, we have



that. In 2008, the National Institutes of Health launched a new program called the Clinical Translational Science Awards (CTSA). About half of current CRCs have a CTSA award that pays for computer programs to make data collection easy. REDCap (Research Electronic Data Capture) is a convenient system that is similar to the popular public site Survey Monkey – except that the REDCap information is encrypted to assure confidentiality of personal health information.

We hope that the CRC Registry will eventually use most of the Alpha-1 Foundation's Clinical Resource Centers across the United States. CRCs specialize in patient care and education for those with Alpha-1. Some CRCs treat lung disease, others liver disease. There are more than 70 CRCs, and more are being added all the time.

To see a list and contact information for Foundation CRCs across the country, visit the Foundation website at www.tiny.cc/Alpha1CRC

We believe that working with both Alphas and CRCs can bring two great results: Many Alphas can find a Clinical

We also need a convenient way to find and use the stored data. MUSC is one of more than 33 medical centers (including some in Europe) who use a program called Integrated Informatics for Biology at the Bedside (called "i2b2" for short).

This computer program allows data that contains no personally identifying information to be kept in a public database where it can be queried by anyone in the community.

We are planning a pilot study involving several of the CRCs that already have the capacity, to make sure the system will work the way we want it to. Lastly, we will need to fill up our database with Alphas who will visit their nearby CRCs, where healthcare professionals will collect and add the information we need – clinical data, images and biological samples to add to the new CRC Registry.

We are working as fast as we can to get the new CRC Registry up and running. We believe the summer of 2012 is the most likely start date.

Eventually, current Registry members will receive a mailed invitation to join the new CRC Registry. To join, you would

make an appointment to visit the nearest Clinical Resource Center. From there a healthcare professional would have you sign a consent form and enter your data into the data warehouse. The data will be checked, made confidential and secure. The final output, with no personally identifying information, will be an open access database full of clinical Alpha-1 measurements. (Open access means the data is public, available to researchers all over the world.) The open access database is the critical component in improving the resources for research in Alpha-1.

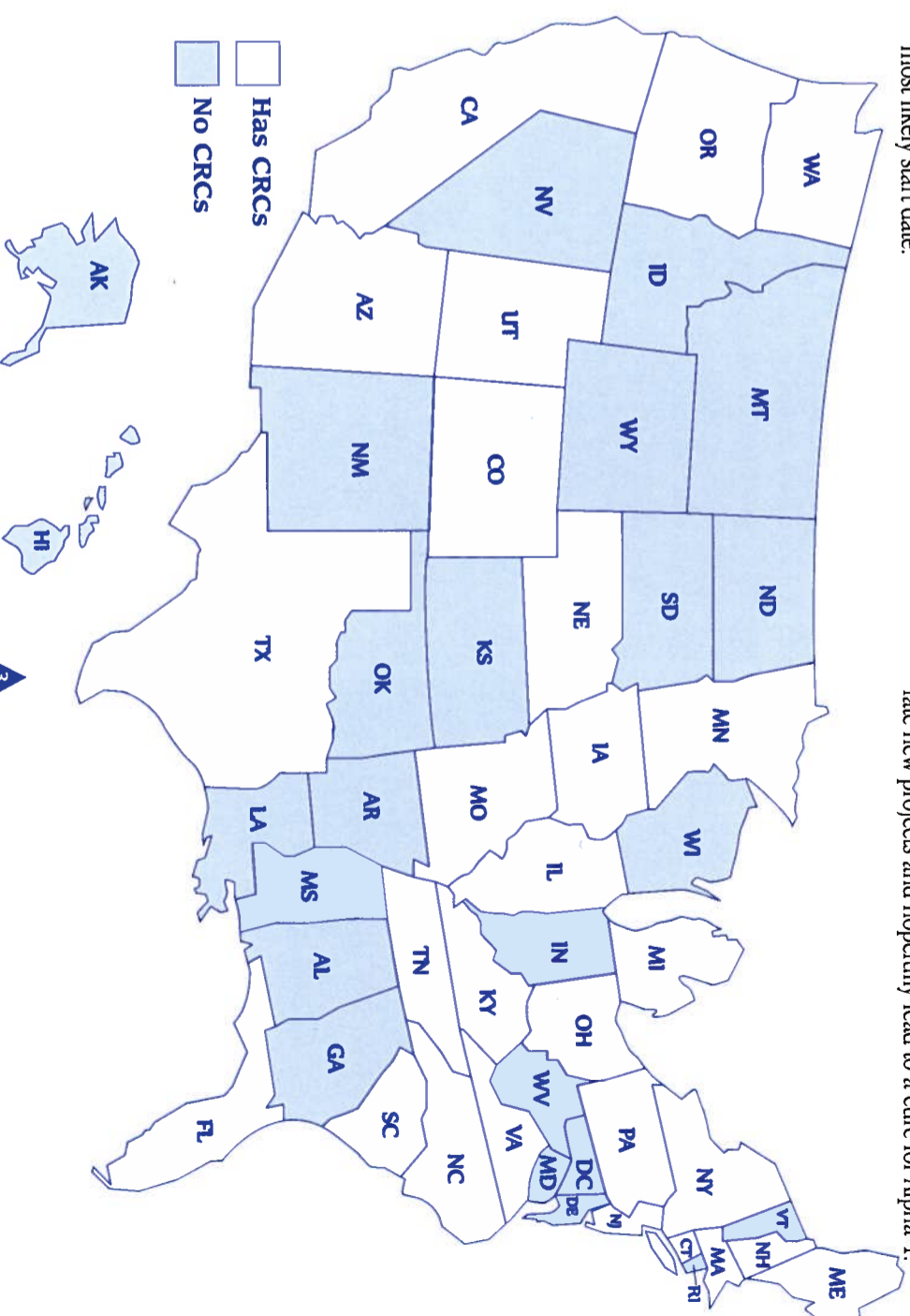
Translational medicine is the practice of moving research projects from the laboratory into the clinic, where people affected by Alpha-1 might benefit. The additional, more detailed data will be a useful resource for researchers to formulate new projects and hopefully lead to a cure for Alpha-1.

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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.



An Alpha tells about volunteering for a research study

By Tom Corron
and Laura Schwarz

For this edition of the Research Registry Update, I had the opportunity to speak and correspond with Tom Corron about his participation in an Alpha-1 research study. Read on and you may find that volunteering for a research study is something you would like to do, too. — Laura Schwarz



I was diagnosed with Alpha-1 in March of 2005. I was getting short of breath climbing stairs and just couldn't do many of the routine things that used to come naturally. At first I thought I was just getting old. That is what a lot of Alphas think at first, and it's what a few of the multiple doctors I had seen over the years told me as well. I was a few weeks away from my 50th birthday when I was correctly diagnosed.

I had never heard of Alpha-1 and didn't really know much about chronic obstructive pulmonary disease (COPD). I was told I had very severe lung damage and there was no cure. And, my doctor warned, I would probably need a double lung transplant within five years. But, he said, we would get started immediately on a weekly treatment called augmentation therapy. These infusions are designed to slow the progression of lung damage and maybe stave off the lung transplant a few years. My doctor could offer no guarantees, of course.

I was hungry for more information about my disorder and attended my first Education Day in Omaha, Nebraska. I had never met another Alpha and was anxious to attend the event and learn as much as I could about Alpha-1. Education Days bring educational programs to Alphas and family members across the United States.

The event flyer for the Omaha Education Day highlighted a presenter by the name of Charlie Strange, MD, from Charleston, South Carolina. I was told that he was one of the top "Alpha docs" in the country. In fact he was a wonderful speaker and a kind and knowledgeable southern gentleman. I was impressed and left armed with knowledge and resources previously unknown to me. Before leaving Omaha, I donated a blood sample to the Alpha-1 Foundation

DNA and Tissue Bank and signed up to become a member of the Alpha-1 Foundation Research Registry based at the Medical University of South Carolina in Charleston.

Prior to the education day, I had no idea what a Research Registry was, or why it was important and especially relevant to our Alpha community. The Registry gave me the opportunity to receive notices periodically, inviting me to participate in various research studies.

Last winter I received a notice from the Registry about the SPARK Study, with contact information in case I was interesting in volunteering. (This study is no longer recruiting volunteers, but you can find the details on this or any other research study by visiting the website www.clinicaltrials.gov. Find this particular study by typing in "NCT01213043" in the search box. The sponsor was Talecris Biotherapeutics, now Grifols.)

Well, I was interested in this study. I called the contact number and found out that I probably qualified. I had Alpha-1 with severe lung damage, and was not excluded by other conditions.

VOLUNTEERING FOR A STUDY

I visited with my pulmonologist and my family physician to evaluate the risks I would face with participating in this particular study. It had some risk -- but so does everyday life. And I was serving the Alpha-1 community by donating my time and helping with this research. In this case, any risk was minor. It was a study comparing a double

dose of augmentation therapy with the regular weekly dose. It was double-blinded, meaning that neither the researchers nor the patients knew which dose they were getting during the course of the study.

Alphabet, a not-for-profit organization that provides clinical administration services to research study sponsors, flew me down to Charleston for the initial evaluation and examinations. They made and paid for all my hotel and travel arrangements. Because I need to use an oxygen concentrator when I fly and I don't own one, they also rented an FAA-approved portable oxygen concentrator for me to use on the plane.

I was so pleased that I was able to participate in this 25-week study and that accommodations could be made for my travel and hotel expenses. Being quite active and involved in the Alpha community as a support group leader in my hometown of Fort Wayne, Indiana, and Alpha-1 Association board member, I had quite a travel schedule to work around over the summer. I needed to be in St. Paul, Minnesota for our Alpha-1 Association National Education Conference in early June.

The Registry staff is helpful and friendly and they made my visits fun. Annie Finley is the research nurse manager and Dawn McGee is the genetic counselor.

Kathy Sivesind from Alphabet handled all my travel needs and has always been great to work with during the study. I can't say enough about the friendly folks at the Coram Infusion Center in Fort Wayne. I reported there weekly for the required infusions and blood tests when I wasn't visiting the lab at Charleston.

During the study I was required to report any changes in my health or medications. I emailed Annie and Dawn with my short notes and updates. They promptly answered any questions I had for them about the study. I even asked them for restaurant recommendations for the evenings I spent in Charleston, and they suggested some wonderful local establishments.

I look forward to participating in more studies in the future.



HELPING WITH ALPHA-1 RESEARCH — Tom Corron, right, with Charlie Strange, MD, director of the Alpha-1 Foundation Research Registry, and Annie Finley, research nurse manager.

What IS the Registry?

The Alpha-1 Foundation Research Registry is a confidential database of more than 3500 people who have Alpha-1 Antitrypsin Deficiency (Alpha-1) or who are carrier phenotypes and are willing to participate in Alpha-1 research. The Registry was established in 1997 in accordance with recommendations of the World Health Organization to facilitate research initiatives and promote the development of improved treatments and a cure for Alpha-1.

THE REGISTRY, A RESOURCE FOR INVESTIGATORS

By establishing a database of individuals with Alpha-1 and promoting its use to the Alpha-1 research community, the goal of the Registry is to allow important research and new therapies to be evaluated in the United States. Source: <http://www.alphaoneregistry.org/investigators/home.html>

August 9, 2011



By Charlie Strange, MD

Ask the Alpha Doc

Alphas with bronchiectasis need to be treated differently

Some doctors say that bronchiectasis is related to Alpha-1 and some don't believe it is associated. What is the truth and does it make a difference?

Bronchiectasis (BRONCH-ee-ECK-ta-sis) is defined as a permanent enlargement of the airways of the lung. This change in anatomy is usually the result of injury to the wall of the airway from an infection or infections. Bronchiectasis can be in some parts of the lung (focal) or widespread (diffuse).

Both the detection and treatment of bronchiectasis are different from many lung diseases.

Besides lung disease related to Alpha-1, other diseases that are linked to bronchiectasis include cystic fibrosis (CF), tuberculosis (TB), and atypical mycobacterial disease (an infection with TB-like organisms that are not spread by human-to-human transmission).

Because the airways are always enlarged in bronchiectasis, mucus that is normally produced by the lung has a tendency to pool in areas of the disease. Mucus is affected by gravity; therefore, bronchiectasis in the lower areas of the lung often has more impact than bronchiectasis in the top of the lung that can drain from the airways by gravity. Mucus is removed from the lung by coughing (yes, everyone coughs!) and by small hair-like projections from the airway cells called cilia, which beat back and forth to bring mucus from the airways at the edge of the lung back to the central airways where it can be coughed up.

If mucus pools in areas of bronchiectasis, it is usually colonized by germs that live there all the time. New germs that are inhaled can land in these warm and dark mucus pools and become part of the infectious world that we all live with.

CONTROLLING INFECTION

Antibiotics never remove all of the germs from these areas of bronchiectasis; but are used to decrease the number of germs when mucus becomes yellow or green and larger amounts of mucus are produced. Bronchiectasis can progress to other airways and extend along affected airways if these infections are not controlled.

The other way to control bronchiectasis is by a good bronchial clearance regimen.

A bronchial clearance regimen is any system that is used to get mucus out of the lung. Common regimens include taking bronchodilators followed by exercise. If the disease worsens, inhalation of salt water (3% or 7% saline) in a nebulizer, or inhaled antibiotics are occasionally used.

The controversy over whether Alpha-1 is associated with bronchiectasis began with a few studies of bronchiectasis patients in which there were no more Alpha-1 deficiency genes than in the normal population. Other studies have suggested that there is an excess of Z genes (most as MZ carriers) in patients with bronchiectasis from atypical mycobacterial disease.

ZZ ALPHAS SEEM AT RISK

More recently, a large study of CT scans from Alpha-1 affected individuals in the United Kingdom found some bronchiectasis in 95% of the ZZ population. How many of these people have a mycobacterial cause of their bronchiectasis is not clear, since these organisms can be very hard to culture.

Nevertheless, this study has solidified the impression that most ZZ Alphas have some areas of airway dilation and are at risk to develop bronchiectasis. This may be one reason that the common courses of 3-7 days of antibiotics do not cure infections for some Alphas.

Unfortunately, the diagnosis of bronchiectasis requires a CT scan. The condition is not seen on regular chest X-rays. Since the average CT scan uses about 40 times more radiation than a chest X-ray, the number of CT scans used to follow the course of the disease can get problematic. If Alphas receive a chest CT scan, they are encouraged to bring a copy on CD or DVD disc on a visit to any new physician who may better understand their disease, since bronchiectasis and emphysema sometimes are not mentioned on the radiology paper reports.

In summary, there is an excess of bronchiectasis in ZZ lung-affected individuals. There may be an excess in MZ carriers, particularly in individuals colonized with atypical mycobacteria. This requires more study.

By Mike Graves

Alpha-1 community-based group plans to help uncover problems with delivery of health care



Congratulations to the recently formed Alpha-1 Community Research Advisory Board (the Partnership)!

The Partnership was selected recently as one of three community partnerships to participate in the Community Engaged Scholars Program sponsored by the South Carolina Clinical & Translational Research Center for Community Health Partnerships.

The program is designed to encourage community-based research by connecting academic researchers with members of a community that want to partner with them on research to meet their healthcare needs. Being selected for training and funding is a great opportunity for the Partnership. The group is now working on a project entitled "Application of CBPR Framework to Assess and Prioritize Socio-political Needs in the Alpha-1 Community".

The Partnership members include two Alpha-1 Association Support Group leaders, Marvin Sineath of South Carolina and Lucinda Shore of Tennessee; two academic clinicians/scientists, Pamela Williams, JD, PhD, RN, and Charlie Strange, MD; two more Alphas, Barbara Warner and Susan Hill; a member of

Columbia, SC. After the meeting, other Alphas agreed to join the project.

The group has expanded since then and now has more than 10 academic and community partners spread across 11 states. The group meets regularly by conference call.

The program is designed to encourage community-based research by connecting academic researchers with members of a community that want to partner with them on research to meet their healthcare needs.

industry, Donovan Quill, an AlphaNet representative, Jim Quill; a genetic counselor, Dawn McGee; and Registry Coordinator Mike Graves.

The Partnership was created in the fall of 2011 when academic nurse scientist Pamela Williams at the Medical University of South Carolina College of Nursing began meeting with Alpha-1 Registry staffers, local support group leaders and patients.

FINDING THE PROBLEMS

The focus of the group is not on finding a cure, but instead addressing the problems with healthcare delivery and unequal availability of care that do not receive much attention from researchers.

The partnership first gained momentum when Williams spoke at a meeting of Sineath's support group in

The goal of the discussions so far has been to identify and prioritize healthcare issues and problems in the Alpha-1 community that could be addressed in future research. Developing a working inventory of issues identified by the Alpha-1 community itself will guide future research taken on by the Partnership.

The group has already submitted a pilot grant to start measuring the perceptions of Alphas about problems in the healthcare system, and has another one it plans to submit soon for Alpha-1 Foundation research funding.

The Research Registry joined the partnership to maximize its connection to the Alpha-1 community. Through the partnership, the Registry plans to promote its mission to support Alphas and carriers who are motivated to participate in research.

If you are interested in becoming a member of the Partnership or have healthcare issues that you would like to see addressed by research, contact Pam Williams at wilpame@musc.edu or 843-792-9902). The Partnership intends to promote Alphas' priorities in research regarding your healthcare delivery, so feel free to share your ideas and concerns.

Two student perspectives on Alpha-1

The articles on these two pages were written by two students working on graduate degrees in genetic counseling at Arcadia University. Both have since graduated with their Master's degrees.

Creating an adolescent guide for Alpha-1

By Brittany McLarney, MS

In 2010 I was enrolled in the master's program in genetic counseling at Arcadia University, looking for ideas for my thesis project. One of my professors mentioned Dawn McGee at the Alpha-1 Association Genetic Counseling Program, and a project she needed help on. That led to my thesis idea: to create a book for adolescents loaded with information about Alpha-1 Antitrypsin Deficiency. I had never heard about Alpha-1, but the idea of making a book for younger people really appealed to me. I volunteered to work on the project right away.

Alpha-1 is a complex genetic condition and can affect all different ages in many different ways. McGee suggested I attend an Alpha-1 Education Day with my classmate Rebecca Cook, who was also doing her thesis on Alpha-1. The Education Day was amazing! Everyone there was ready to help me learn about Alpha-1 and give opinions about what may be important in a book for adolescents. I took many notes and left the conference with tons of educational materials. It was clear from that first day, meeting people with Alpha-1, that this is a close community. Everyone seems interested in research and is ready to help in any way they can.

I spent my summer after that semester writing the book. I had worked a lot with adolescents in a volunteer organization for high-school-age teens called Quixote Quest, so I was excited to write the book. But the book was harder than I anticipated.

WHAT TEENS NEED TO KNOW

I spent most of the summer debating what people in the age range from 13-16 would need to know. What was going on in their lives? What was important to them? What would they understand? I spent a great deal of time thinking about my volunteers in Quixote Quest and what I thought they

would understand and want to know about a health condition. I used that experience to measure what I thought an adolescent in the Alpha-1 community would understand and want to know.

My goal was to make the book both for adolescents who were already a part of the Alpha-1 community, and

also for those who were new to the diagnosis. I wrote many drafts for the book with McGee's guidance, and I'm proud of the outcome. It was exciting to see images the illustrator drew for the pages of the book I put together.

The book, whose working title is **Not the Only Alpha-1**, was still being edited as I write this, and I can hardly wait to see the final product.

After the writing, I had to get approval to contact adolescents with Alpha-1 to survey what they liked about the book and what should be changed. The goal was to send out the draft electronically, with the text and rough drawings. This way, if the results from the survey showed that changes should be made, it was still possible to edit the book before it was printed. The approval process took longer than I expected and I only had time to obtain two responses to the survey before I graduated. I am hoping to be able to continue to get feedback on the book so that it can be as useful as possible. The two responses I did receive were both very positive and thoughtful. The participants said they liked the book and gave specific details about what they liked. They also did not hold back about what should be changed. With more great responses like this, the book should be a great tool for adolescents in the Alpha-1 community.

Working on the book was very rewarding and I hope to stay in touch with the Alpha-1 community and to continue working on this project.



Evaluating the Alpha-1 Family Awareness Video Series

By Rebecca Cook MS

When the Alpha-1 Association set out to make four educational videos, their goal was to provide the Alpha-1 community with a better understanding and awareness of the condition. The videos include interviews with

Alphas and members of their families, as well as many of the physicians caring for them.

As a genetic counseling graduate student, I did my thesis on a study to determine how useful the videos were in increasing people's knowledge of Alpha-1. I had never heard of Alpha-1 before beginning the project, but was looking forward to becoming more involved in the community and learning about the support and resources available to Alphas. We conducted our study in 2010 at the annual Alpha-1 Association National Education Conference in Orlando, Florida. We asked anyone attending the conference to watch the videos and answer a few brief questions about Alpha-1 before and after watching it. If the viewer had learned from the video, then the number of questions answered correctly should increase after watching the video.

In all, 86 people volunteered to take part in our study. Alphas, their family members and caregivers, as well as industry and non-profit workers all participated. After analyzing our results, we found that overall the videos increased knowledge.

ALPHAS WELL-INFORMED
Interestingly, a majority of individuals answered both pre-video and post-video questions correctly -- showing that much of the Alpha-1 community is already knowledgeable about the condition.

We also asked participants to tell us what they thought of the videos. In general people found the videos to be quite helpful. We also asked what people liked most and what they liked least. The responses were overwhelmingly positive.

Such a positive and motivated perspective seems to be common among Alphas and their loved ones. They would tell me their plans to take the videos to their local doctors so that more health care professionals would be aware of Alpha-1 and know how to help those affected. My classmate Brittany and I were amazed at the energetic and dedicated people we met at Alpha-1 meetings. From the first day I began working with the community, I noticed that everyone I met or worked with was enthusiastic about answering my questions and helping with the project.

I cannot thank the Alpha-1 Association, the Alphas, their family members and caregivers enough for welcoming me into their community and helping me with my graduate work. I hope to have more opportunities to serve them all as a genetic counselor and advocate in the future.



CRC specialists discuss future of research and family testing

By Dawn McGee, MS, CGC



The Alpha-1 Foundation hosted a conference for its Clinical Resource Centers (CRCs) in St. Paul, Minnesota, in June. This was the second in a series of semi-annual meetings designed to gather together the CRCs around the country to update them on the latest research and resources for the Alpha-1 community. It also gives the CRCs a chance to network with other specialists who share the same passion for caring for families with Alpha-1.

This CRC meeting was specifically scheduled to be held just before the Alpha-1 Association's 20th National Education Conference. The timing created an opportunity for patients to meet face-to-face with Alpha-1 experts from around the country, and just as importantly, the experts to meet the people that all their hard work is directly benefiting.

Currently there are more than 70 CRCs around the United States specializing in Alpha-1 patient care and education. Some CRCs specialize in lung disease and others in liver disease, both pediatric and adult.

Robert Sandhaus, MD, PhD, clinical director of the Foundation and medical director of AlphaNet, spoke about the history of the CRC program, the status of the program today, and what lies ahead for the CRC program. He also discussed the controversial 2010 Cochrane Report on augmentation therapy and some ongoing concerns about that publication.

Michael Campos, MD, who conducts research and sees Alpha-1 patients as a CRC in Miami, discussed the importance of targeted detection and the Alpha-1 Foundation's detection efforts, and reported on his recent study examining the overall results of testing reported by many sources in the United States.

Adam Wanner, MD, Foundation scientific director, described the latest research studies in Alpha-1, what we still hope to discover, and efforts to translate our basic research successes into new therapies and potential cures for Alpha-1.

Jeffrey Teckman, MD, a pediatric liver specialist at St. Louis University School of Medicine in St. Louis, MO, talked about liver disease in Alpha-1 and current and future research initiatives. He said a study of the natural history of Alpha-1 liver disease is needed and long overdue.

Charlie Strange, MD, director of the Alpha-1 Foundation Research Registry, talked about the future of the Registry and plans for a pilot program to create a CRC Registry, with more medical data from healthcare professionals who care for Alphas. Strange led a breakout session that was an open discussion with the group regarding plans to design the new CRC Registry.

Wanner and Dawn McGee, MS, CGC, led a second breakout session to discuss the importance of family testing. McGee, program director of the Alpha-1 Association Genetic Counseling Program, discussed the program and suggested ways it can be a resource for the CRCs and their patients. This session also included an open dialogue with the CRC healthcare professionals, who discussed what additional services they need from the Genetic Counseling Program and the Foundation.

Overall, the meeting allowed new CRCs to meet some veteran Alpha-1 physicians and researchers, and facilitated new ideas for research and collaboration between Alpha-1 experts from around the country.



Adam Wanner, MD



Michael Campos, MD

Know your letters? (Your Alpha-1 letters?)

If you have Alpha-1 or are a carrier of Alpha-1, it is important to know your genotype. Your Alpha-1 genotype is a combination of the genes you received from your parents, one from your mother and one from your father. If you are deficient, your genotype may be ZZ or SZ or a combination of less common genes. The most common genotypes for carriers are MZ and MS.

Knowing your genotype helps predict the likelihood of disease progression and assists the Registry when we invite you to take part in a research study. If you don't know, ask your doctor for the test result.

If a member of your family needs Alpha-1 testing, you can refer them to our toll free number (1-877-886-2383) for the free, confidential ACT Study. They will receive their genotype and their estimated Alpha-1 protein level. If the test indicates the person is an Alpha or carrier, a Research

Email: quick and easy way to volunteer for research

Looking for a quick and easy way to participate in Research? Send us your email address!

This will be a big help in updating our records, too. Email addresses change often, and keeping them up to date may be the hardest thing to track when you're dealing with thousands of people.

Just send us a quick email at alphaone@muscedu with your current preferred email address. If you're not at your computer, you can just call us at 877-887-2383.

The Registry will be contacting you soon with research questionnaires and we would like to go paperless. It is much more convenient and efficient to send out surveys through an email blast instead of the standard paper copy through U.S. mail.

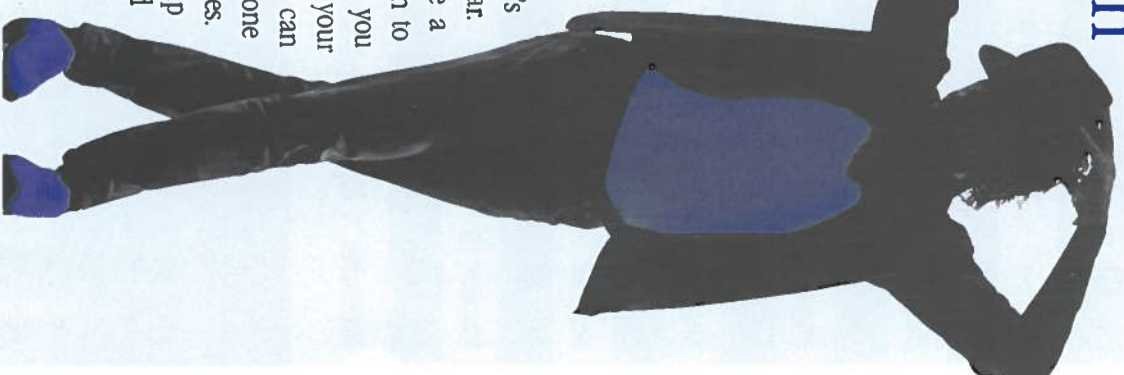
Online questionnaires are a quick and easy way to make a contribution to research. Electronic responses to surveys help us put information directly into our database, which makes it much easier for research investigators to compile the data.

So please go to your computer and send us an email – so you can help with our next research study.

Celebration of Life...

Registry application will be included with their result letter. We urge these people to join the Registry so that they will be included in our invitations to take part in Alpha-1 research. Being invited to take part in a research study doesn't mean you're obligated. You choose whether to volunteer or not. It's always your choice. It is free and confidential to join and truly assists us in our research to find a cure!

MUSIC THROUGH THE AGES is the theme of the Alpha-1 Foundation's **Celebration of Life** this year. Everyone is invited to have a fine dinner, dance and listen to some great music – and if you like, dress in the fashion of your favorite musical decade. You can also play a round of golf at one of Miami's premier golf courses. The Foundation's flagship fundraising event will be held as usual at the Indian Creek Country Club, Friday, April 27. For information on Celebration of Life and all Foundation fundraisers, contact Angela McBride at amcbride@alpha-1foundation.org or call 305-567-9888, Ext. 233. See the full Calendar of events, page 12.



Calendar of coming events

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

March 24	Education Day	Birmingham, AL	Marlene Erven: mserveren@alpha1.org
April 14	Alpha-1 Hero Walk	Richmond, VA	Pam Van Scoy: vaalpha1herowalk@yahoo.com
April 21	Education Day	Kansas City, MO	Marlene Erven: mserveren@alpha1.org
April 23	Friends for a Cure - Golf	St. Augustine, FL	Richard & Sarah Johnson: Sarah_shirk@comcast.net
April 27	Celebration of Life—Golf & Dinner	Miami, FL	Alpha-1 Foundation: amcbride@alpha-1foundation.org
April 28	Book Sale	Fort Collins, CO	Glen Perkins: gaperkins1@msn.com
May 12	George Washington Bridge Walk	NY/NJ	Lori Tartell and Joe Reidy: JoeReidy@Verizon.net
May 21	Alpha-1 Foundation Research Awards — ATS International Conference	San Francisco, CA	Angela McBride: amcbride@alpha-1foundation.org
May	Get The Scoop on Alpha-1	Denver, CO	Judy Simon: sajdsimon@comcast.net
June 8 - 10	National Education Conference	Seattle, WA	Marlene Erven: mserveren@alpha1.org
June 10	The Great Divide Mountain Bike Race	Canada - USA	Michael Intrabartola: Firstgiving Page
July	Get The Scoop on Alpha-1	Johnston, IA	Peg Iverson: pegiver@mcnsi.com
August	Alpha-1 Walk & Ice Cream Event	Fairmont, MN	Julie Lilienquist: julie@norwexwithjulie.com
August	Paul Healy Memorial Golf	Boston, MA	Bob Healy: bobhealy125@msn.com
August 18	Education Day	Lebanon, NH	Marlene Erven: mserveren@alpha1.org
Sept. 13	Alpha-1 Golf Greenwich Country Club	Greenwich, CT	Ken Irvine: ken.irvine@scotiabank.com
Sept. 22	Education Day	Milwaukee, WI	Marlene Erven: mserveren@alpha1.org
Sept. 28-30	Team Alpha-1 Escape To The Cape	Cape Cod, MA	Angela McBride: amcbride@alphaone.org
October 13	Education Day	Portsmouth, OH	Marlene Erven: mserveren@alpha1.org
November	Alpha-1 Step Forward For a Cure	Jupiter, FL	Gordon Cadwgan: gcadwgan@comcast.net
November	Alpha-1 Step Forward For a Cure	Myrtle Beach, SC	Angela McBride: amcbride@alpha-1foundation.org

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 more than \$42 million to support Alpha-1 Antitrypsin Deficiency research in almost 90 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 70 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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